

# treatment issues for women



Writing for this brochure was a collaborative effort by six women. We thank each of the writers for sharing her knowledge and experience to help make this publication possible.

Written by:

Jen Curry  
Angela Garcia  
Jennifer McGaugh  
Heidi Nass  
Cathy Olufs  
Claire Rappoport

Edited by: James Learned

Graphic Design: Joy Episalla

Special Thanks: Louise Binder, Constance T. Chang, Susan Cu-Uvin, MD, Judith Currier, MD, Ann Danoff, MD, Jerome Ernst, MD, Lisa Frederick, Steven Grinspoon, MD, Tim Horn, Donna M. Kaminski, Mark Milano, Jeff Scheuer, Tracy Swan, Claire Wingfield, and ACRIA's Community Advisory Board.

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230 West 38th Street, 17th Floor, New York, NY 10018  
212-924-3934 FAX 212-924-3936  
[www.acria.org](http://www.acria.org)

J Daniel Stricker, *Executive Director*

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# Introduction

If you are a woman living with HIV, you probably have a lot of questions. We all do. Since the first studies of HIV in the 1980s, many treatment advances have been made. However, many questions remain about how HIV and its treatments affect women and men differently. Few sources of treatment information and support focus on HIV-positive women.

This booklet was written for women living with HIV. Some of the conditions discussed here affect men as well. Due to limited space and the availability of information about various treatment issues in other places, we have chosen to focus on certain HIV-related conditions and health issues as they specifically affect women, including hormones, anemia, lipodystrophy, and bone density – issues that greatly affect our quality of life.

Whether you're reading this booklet for yourself or for someone else, we hope you find useful information here. We also encourage you to keep asking questions, learn as much as you can about HIV, and be involved in decisions about your body and health.

To learn more about drugs used to treat HIV, treatment strategies, or anything covered in this booklet, you may want to read some of the free treatment publications listed in the resource section on page 29. Some of these resources discuss treatment issues as they specifically relate to women. If you need more detailed information or want to talk about a particular subject – such as pregnancy – you may also want to contact one of the women's agencies listed, where you can speak with a treatment educator or advocate for further information and support.

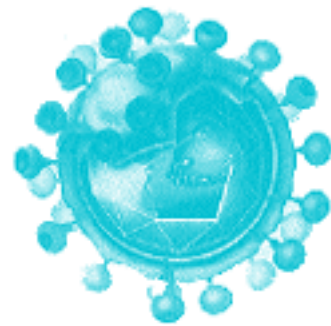
While there are references to specific HIV treatments throughout, this booklet does not discuss antiretroviral therapy in detail. Decisions about whether to start, stop, or switch regimens are not covered.

# Hormones and HIV

The endocrine system is made up of numerous cells and organs, each of which carries out important functions that help regulate your body and keep it in balance. Hormones are chemical substances that act like messengers, traveling through the bloodstream between the glands that make them and the cells and organs they act upon. Some hormones help specific organs – like the liver – function by speeding up or slowing down chemical reactions. Others act on cells, proteins, and tissues, triggering growth, metabolism, sex drive, and fertility. Hormones play an important role in our overall health. Since women living with HIV may be at increased risk for certain hormone problems, it's important to know how you might feel if your endocrine system isn't functioning properly.

Estrogen, progesterone, and testosterone are three of our main sex hormones. They are part of a class of hormones called steroid hormones and regulate many aspects of our growth. The ovaries make progesterone, most of the estrogen, and some of the testosterone in our bodies. The adrenal glands (located just above the kidneys) also make testosterone and some estrogen. Together, these three hormones influence our sexual desire, behavior, and ability to have children – along with our mood and overall body composition. Levels of estrogen, progesterone, and testosterone fluctuate throughout the month and decrease over time as a part of the aging process.

Balance among these hormones is very important, since changes in the amount of one can affect levels of the others. For example, a drop in estrogen can affect levels of testosterone, progesterone or related hormones such as DHEA. In order for estrogen, progesterone, and testosterone to do what they're supposed to, our bodies need to make these hormones regularly *and* get rid of them when we don't need them anymore. Otherwise, many bodily functions can be disturbed.



## How Does HIV Change the Picture?

HIV itself can affect the body's ability to produce and maintain healthy hormone levels. Changes in the balance of estrogen, progesterone, and testosterone can affect HIV-positive women in many ways. In some cases, this may lead to:

- Menstrual irregularities
- Weight loss
- Hot flashes
- Changes in mood and behavior, including sleep patterns
- Decreased bone density
- Fatigue

- Depression
- Decreased sexual feelings or difficulty having orgasms
- Vaginal changes (lining of the vagina becomes thin, dry, and may tear easily)
- Difficulties getting pregnant or having a healthy pregnancy

If you're having *any* of these symptoms, ask your healthcare provider whether your hormones might be out of balance. Too often, we assume that things like fatigue and sexual problems are just part of living with HIV, but they may not be. Without follow-up, important hormone problems (and solutions) can be missed.

Even without symptoms, you may want to get your hormone levels measured. An initial baseline measurement – when you're first diagnosed or anytime afterwards – can help your provider detect changes in the future should symptoms occur. This isn't usually part of routine care and can be expensive. Since many experts recommend baseline measurements, ask your provider for them.

## Testosterone

Many people think of testosterone as a male hormone, but it's also extremely important in women. Testosterone is critical for healthy skin, bones, organs, and muscle. Without it, we'd have a hard time maintaining our sex drive and energy levels.

HIV can lead to low testosterone levels in men and women. Low levels are more common in women with low CD4 counts, women experiencing wasting syndrome, and postmenopausal women. Some drugs used to treat HIV-related conditions – Cytovene (ganciclovir), Megace (megestrol acetate), Nizoral (ketoconazole), and possibly others – can also lower testosterone levels.

Because women generally have so much less testosterone than men, our bodies are sensitive to smaller degrees of change in the amount of testosterone. A small drop may not be noticed by a man but could cause symptoms in a woman. When testosterone is low, you can feel tired, depressed, moody, or weak. You may not feel much like having sex, either. Since low testosterone can also increase your risk for weight loss – including loss of muscle – it's important to maintain healthy testosterone levels.

## Checking Your Testosterone Levels

Testosterone circulates in our blood in three forms. Two forms – about 98% – are bound to proteins. Most of this testosterone is inactive. The remaining 1-2% is not attached to any proteins and circulates freely in our bodies. This “free testosterone” is immediately available for your body to use. **Total testosterone** and **free testosterone** are the two standard blood tests used to measure testosterone levels in women. Total testosterone measures both the free and bound testosterone in your blood.

Medicaid and private insurance cover both tests, but it can take effort to get them ordered. You may need to find an experienced provider who's willing to listen, or get a referral to an endocrinologist. Most providers have limited experience measuring testosterone in women. Since there's not a lot of information on testosterone therapy in women with HIV, some providers are unfamiliar with its use to treat weight loss, low sex drive, or other HIV-related symptoms in women. Regardless of where you get care, you have a right to request tests you feel are necessary for your health and to discuss the risks and benefits of available treatment options.

Testosterone levels peak in the morning and vary from hour to hour, so always have your blood drawn in the morning using the same lab whenever possible. Since levels of free testosterone are the ones most commonly affected by HIV, ask for a *free testosterone test* (they're not automatically done). The ratio between your free and total testosterone levels is also important. In addition to age, stress, and other factors, testosterone levels can be affected by related steroid hormones. If your testosterone levels are low, your provider may need to assess them in the context of your overall hormone levels and other measures of endocrine function to figure out what's going on.

There's still debate about what's considered a normal testosterone level for a woman. Without knowing what's normal, it's difficult to know what's low. Plus, what's low for one woman is often high or normal for another. What we *do* know is that any unexplained drop in your testosterone level should be investigated.

Most major labs use a very wide reference range for normal, which can vary a lot between labs. Even though some labs list 15 ng/dL as the low end of the range for premenopausal women, many providers feel that a testosterone level below 20 ng/dL can be too low for a woman to maintain her sex drive and energy level. In women with HIV, it often takes more than one measurement, along with symptoms, to diagnose a low or deficient testosterone level. So in addition to checking total and free testosterone levels, pay attention to how you're feeling, especially your sex drive, energy level, overall mood, and weight.

## Treatment Options

Testosterone replacement has been offered to men with HIV for years to treat weight loss and low sex drive, but there is limited experience using it in HIV-positive women. In the last few years, controlled studies have shown that HIV-positive women using replacement testosterone often see their levels return to normal and their symptoms partially or fully resolve.

We need to learn more about dosing and possible long-term effects of testosterone use in women with HIV. So far, research suggests that testosterone therapy may be *especially important* for women who have wasting or low weight, an increase in fat compared to muscle, and/or bone density loss. If you're considering testosterone, make sure your provider has experience in this area. Otherwise, get a referral to an endocrinologist.

Testosterone supplements are prescribed as injections, tablets, patches, gels, or creams. Gels and creams don't have specific approval for use in women, but women often use the gels or creams prescribed for men, in smaller amounts. Each form has pluses and minuses in terms of cost, ease of application, and the ability to maintain consistent testosterone levels in your body. Too much testosterone can cause mood changes, a swollen clitoris, and more facial hair. If you take testosterone, it's important to minimize side effects while keeping levels in the normal range. Replacement options include:

- **Oral:** Low-dose testosterone pills are available through compounding pharmacies. Oral testosterone is processed through your liver and shouldn't be taken if you have liver or gall bladder disease.
- **Topical:** Alternatives to pills include patches, creams, or gels. Patches are like small Band-Aids that you apply directly to your skin. They need to be changed often – every day or every few days. Patches deliver consistent amounts of testosterone to your bloodstream but are only available in a limited range of doses. With creams, your provider can set the dose to control the precise amount of hormone you receive. Testosterone cream is sometimes used to treat low sex drive and vaginal dryness.
- **Intramuscular:** Testosterone injections are rarely used in women.

Since little is known about the best doses of testosterone in women, you may want to begin with a very low dose and have your levels checked frequently. It can take some work in the beginning to find the best dose for your body. Too much testosterone over time may lead to problems with blood fats and liver function, so it's important to have an experienced provider closely monitor the testosterone dose and levels in your body.

## Estrogen and Progesterone

Estrogen regulates your ovaries, causes monthly changes in your uterus, cervix, vagina, and breasts, and is important for vaginal and emotional health. Estrogen also plays a role in insulin release, along with other metabolic and cardiovascular functions. Progesterone – nicknamed the “feel good” hormone – affects your mood, sex drive, and metabolism and is key during pregnancy. Progesterone opposes the effects of estrogen in different parts of your body, so balance between these two hormones is very important. Too much progesterone, for example, can lead to mood changes and depression in some women.

Estrogen levels normally decline as we age. For 5 to 10 years leading up to menopause (called perimenopause), estrogen levels fluctuate significantly. Once you reach menopause, your body produces far less estrogen, progesterone, and testosterone, and levels decline accordingly.

Women with HIV sometimes experience early menopause and/or related symptoms of hormonal imbalance. It's still unclear exactly how HIV and antiretroviral drugs contribute to estrogen deficiency and/or conditions associated with low estrogen like early menopause. Since so many factors (including age, use of street drugs, medications, and nutrition) affect the way your body makes, uses, and eliminates these hormones, it can be hard to pinpoint the reason for changes in hormone levels. More research is needed to understand the mechanism of endocrine dysfunction in women with HIV.

When estrogen is low, we can be more prone to missed periods, vaginal infections, changes in the lining of the vagina, and pain during sex. Years of premature low estrogen – regardless of the cause – may increase a woman's risk for high cholesterol and triglycerides, heart damage, and bone loss. It's important to identify estrogen deficiency and consider ways to restore endocrine balance given that HIV and some drugs used to treat it create additional risks for these same conditions.

*Ask your healthcare provider to check your hormone levels if you have: missed periods; shorter or longer menstrual cycles; worsening pre-menstrual symptoms; vaginal dryness; problems sleeping; fatigue; or hot flashes.*

### Checking Other Hormone Levels

If you're much younger than fifty and are missing your periods or having difficulty getting pregnant, it's important to figure out what's causing the problem. Specific blood tests can help your provider rule out certain factors like menopause and may give insight about the causes of any symptoms you're experiencing.

Together, luteinizing hormone (LH), follicle stimulating hormone (FSH), and estradiol (a type of estrogen) regulate your periods and your ability to get pregnant. Blood tests of LH and FSH are often used to determine whether a woman is entering menopause, but levels fluctuate, and these tests won't tell the whole story for HIV-positive women. If you're having levels checked, be sure to go the extra mile and check estrogen and perhaps progesterone as well. These tests aren't routinely done, and your provider may need to send your sample to a special lab. Since test results vary a lot between labs, ask your provider to use the same lab every time.

The timing of your test is equally important since levels of these hormones vary during the normal course of a menstrual cycle. Estrogen levels are highest in the middle of your cycle, while progesterone levels peak later, around day 21. To check estradiol and FSH levels, *have blood drawn on day two, three, or four of your period* (two, three or four days after you start to bleed). Ask your provider about the best time to have blood drawn for an LH level.

To get a sense of what's normal for you, you may need to measure estrogen several times a month or measure estrogen, LH, and FSH levels over several menstrual cycles. Results are most reliable if you have your blood drawn at the same time

of day *and* on the same day of your cycle each time. If your FSH level is high (above 20 mIU/ml) for several months, you may be approaching menopause.

Age, stress, and medications also affect estrogen levels. As with testosterone, we don't have clear guidelines for what's normal. Plus, it's possible to have symptoms with a normal estrogen level if there's an imbalance between estrogen and related steroid hormones. For these reasons, it's important to pay attention to how you feel and discuss *any* symptoms with your provider.

### **Hormonal Therapy: Estrogen and Progesterone**

Hormonal therapy is a general term that most commonly refers to the use of estrogen and progesterone – either with or without testosterone – to relieve menstrual and perimenopausal symptoms and, less often, to restore balance to overall hormone levels in the body.

In the past several years, our understanding of the risks and benefits of hormone replacement therapy (HRT) – defined as the long-term use of systemic estrogen and progesterone to replace levels after menopause – has changed dramatically. Estrogen and progesterone therapy provide symptom relief for women during menopause. But, for close to twenty years, many healthcare providers believed that prescribing estrogen and progesterone also had potential long-term health advantages in older women, even though the evidence was limited. Due to this belief and marketing by hormone manufacturers, estrogen and progesterone were widely prescribed to symptomatic women ages 45-70 as long-term “replacement” therapy in the years leading up to and after menopause.

However, in 2002, data from several large multi-year controlled studies that began in the early '90s found that long-term estrogen therapy was associated with an increased risk of blood clots and stroke in older postmenopausal women and did not protect against heart disease. The same studies found that estrogen/progesterone therapy slightly *increased* the risk of heart attack, stroke, and certain forms of breast cancer. On the other hand, the treatment offered slight protection against colon cancer and hip fractures. In the past, estrogen was also prescribed to prevent or treat osteoporosis. Since the studies saw increased problems with heart disease and stroke for women using estrogen/progesterone, many women now prefer to use other medications for bone loss (see page 16).

Hormonal therapies are now most often used to: relieve menopausal symptoms like hot flashes and vaginal dryness; improve heavy or irregular menstrual bleeding; prevent pregnancy; and less commonly to supplement progesterone and estrogen levels around the time of menopause. Estrogen and progesterone can be used for short periods (one to three years) to relieve the most intense symptoms of early menopause and may be cautiously used for longer periods if the benefits outweigh the risks.

## Hormonal Therapy and HIV

Sometimes, younger women with HIV have irregular periods or stop having periods altogether, years before menopause is expected. It's important to recognize that using estrogen and progesterone replacement in these younger women, including HIV-positive women who've had their ovaries or uterus removed due to cancer, may have different benefits and risks than when hormonal therapy is used in older women.

Most of what we know about the risks and benefits of HRT comes from the studies of older postmenopausal HIV-negative women who used estrogen/progesterone for more than ten years. Nonetheless, many younger HIV-positive women use either hormonal contraceptives or estrogen/progesterone therapy to correct HIV-related imbalances in hormone levels and to relieve symptoms during and after menopause. A few studies have shown that women with HIV who use hormone therapies to restore hormonal balance experience more consistent sleep, higher energy level, better mood, and improved quality of life.

The increased risks for stroke, breast cancer, and heart attack seen in the HRT studies may be an issue if you're using estrogen/progesterone for many years. *But the level of risk depends on many individual factors, and hormone treatments are still an important option for some women with HIV.* Oral estrogen is processed through your liver and gall bladder, so it isn't recommended if you have liver or gall bladder disease. When used without progesterone, estrogen can increase the risk for uterine cancer, so it's important to take both if you still have a uterus. If you have a history of – or are at high risk for – diabetes, uterine fibroids, or blood clots, carefully consider whether HRT is safe for you. As discussed above, long-term use of estrogen (5+ years) has also been linked to an increased risk for certain forms of breast cancer, stroke, and heart disease. If you've had breast or uterine cancer, you should not use estrogen/progesterone unless you've discussed this choice with your provider.

### ***Types of Estrogen/Progesterone Therapy***

Estrogen and progesterone treatments come in many forms. The delivery system you choose plays a big role in how well you tolerate hormonal therapy. When deciding, you and your provider should consider your replacement needs; possible side effects; your personal and family medical history, including breast cancer, blood clots, and heart disease; the health of your vagina, cervix, and uterus; and other factors like your weight. Replacement options include:

- **Oral:** Women who need to replace estrogen or progesterone throughout the body often use tablets. After tablets are swallowed, they're broken down in the stomach and absorbed by the intestines. This digestive process makes it necessary to use a higher dose than with the other forms. Tablets come in many different doses, including a combination of estro-

gen and progesterone. If you're considering tablets, you may want to start with the lowest possible dose. Some pharmacies (called compounding pharmacies) can make lower-dose tablets if you need a dose that isn't available at your pharmacy.

- **Creams:** Creams are applied directly to the skin, such as on your upper thigh, abdomen, or vagina. The hormone is absorbed directly into your bloodstream, so doses tend to be much lower than with tablets. Creams are sometimes more costly, but they are an important option because they allow you to find the dose that's best for you.

Progesterone creams can be used alone (for women who need progesterone but not estrogen) or with estrogen creams. Estrogen creams may contain up to three types of estrogen. They are often used to treat specific symptoms like vaginal dryness and atrophy. Creams applied only to your vagina won't protect against bone loss or other long-term complications related to low estrogen. They contain a low dose of estrogen and don't provide consistent levels throughout the body.

- **Patches:** Like creams, patches deliver the hormones through the skin to the bloodstream, bypassing your digestive system. This makes them a safer alternative to tablets for women with liver or gall bladder disease. They look like Band-Aids and can be worn anywhere on your body (on your thigh, stomach, or butt for example). They need to be changed every 3-7 days, sooner for some women. Patches deliver consistent hormone levels into the bloodstream but are not available in a range of doses.
- **Injections:** Progesterone injections are sometimes given as an alternative to birth control pills. When used to prevent pregnancy, Depo-Provera (a synthetic progesterone) is injected once every three months.

There are many questions about using hormonal therapy in HIV-positive women, including: whether to use it at all; the right dose/schedule to minimize side effects; how long to use it; and interactions between hormone replacements and HIV treatments. Although interactions between HIV medications and hormonal regimens were finally beginning to be studied recently, much of this research was stalled by the data that emerged in 2002. There are currently no specific dosing recommendations for women using estrogen and progesterone regimens and HIV medications at the same time. *If you're considering hormonal therapy, it's extremely important to have a full health evaluation – including a thorough physical exam – by your HIV provider and your gynecologist to determine whether this is a safe option for you.*

### ***Alternatives to Hormonal Therapy***

There are prescription and non-prescription alternatives to hormonal therapy that may relieve specific symptoms associated with hormonal imbalance. Two types of prescription drugs, bisphosphonates and selective estrogen receptor modulators (SERMs) provide protection against bone loss without the added risk of breast and uterine cancer. However, these drugs don't replace estrogen, so they won't help with hot flashes, vaginal dryness, depression, or other symptoms of low estrogen. Effexor (venlafaxine), used to treat depression and anxiety, has been shown to reduce hot flashes in some women, at least for a few months.

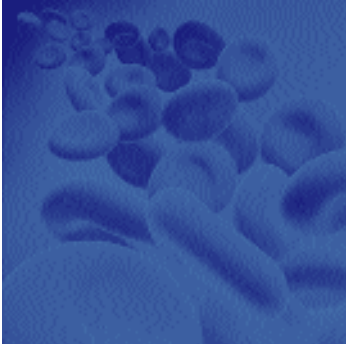
There are also non-prescription remedies for pre-menstrual and menopausal symptoms. Soy contains natural estrogens. Soy products like soymilk, soybeans, and tofu may help relieve symptoms, and some women report positive results using them. Increasing the amount of omega-3 fatty acids (found in eggs, salmon, trout, walnuts) in your diet or by supplement (such as evening primrose oil) may help with menstrual cramps, bloating, swollen breasts, and mood changes. Some women report relief from magnesium for cramps and irritability; vitamin B complex or calcium for bloating; and vitamin E for hot flashes and swollen breasts. Others do not experience full relief from these therapies. Getting enough sleep, regular exercise, acupuncture, and/or yoga may also provide some relief from pre-menstrual and menopausal symptoms.

If you're considering supplements, be sure to consult your providers. They may be able to help you figure out the best dose, suggest certain formulations, and tell you about interactions between supplements and other medications you're taking.

## **Anemia**

Anemia is a shortage of red blood cells or hemoglobin, a protein inside red blood cells that carries oxygen from your lungs to the rest of your body. If oxygen is in short supply throughout your body, you'll feel tired. You may also feel light-headed or short of breath. Other symptoms include palpitations (irregular heart beat), unusually pale skin, and loss of appetite.

Anemia is extremely common in HIV-positive women. A chronic infection like HIV puts stress on your bone marrow, where red blood cells are made. Some HIV medications can also cause anemia. Anemia is more common in women, people with low CD4 counts and/or high viral loads, and African Americans. It's very important to treat anemia, since the risk of HIV disease getting worse is greater in people with anemia.



Anemia can have many different causes, including:

- A thyroid that's not working right;
- Bleeding (heavy menstrual or internal);
- Bone marrow damage or infection;
- Deficiencies in key vitamins and minerals needed to make red blood cells – iron, folic acid (folate), B12, and selenium;
- Kidney damage; and/or
- Medications: AZT (Retrovir, or as part of Combivir or Trizivir), ribavirin, amphotericin, and many others.

*Diagnosis:* To figure out if you're anemic, ask your healthcare provider for a complete blood count (CBC). The CBC includes total red blood cell counts, size and shape of red blood cells, hemoglobin, and hematocrit. *Hemoglobin levels for women should be at least 12 g/dL.* A hemoglobin level less than 6.5 g/dL is too low to keep your organs functioning properly. The hematocrit value is the percentage of blood volume that is made up of red blood cells. In women, red blood cells should make up about 35% to 46% of the total blood volume.

Treatment for anemia depends on what's causing the problem. It's important to stop any chronic bleeding, including frequent nosebleeds, hemorrhoids, and excessive bleeding during your periods, and to address any shortage of iron, folic acid, or vitamin B12.

Before supplementing with vitamins and minerals, make sure you know which nutrients are deficient. Iron is often low in women. Taking iron tablets can restore levels, but too much iron isn't a good thing, especially if you have severe liver damage. You can usually get enough iron by eating red meat, seafood, fish, and fortified bread and cereals. Folic acid is found in dark greens, asparagus, lima beans, spinach, and beef liver. Vitamin B12 levels are often low in people with HIV, and some of us aren't able to absorb this vitamin from food or oral supplements. If your B12 levels are low, you may need B12 injections or a formulation of B12 that you put under your tongue – no matter how much you get in your diet.

If anemia is caused by a medication, it may be possible to switch to a different drug or – in some cases – lower the dose. If that's not possible, anemia can be treated using erythropoietin (EPO), a hormone made by the kidneys that stimulates your body to make red blood cells. Synthetic EPO (Procrit or Epogen) is injected under the skin, usually once a week, to help your body make new red blood cells. It may take two to eight weeks for your counts to return to normal. Blood transfusions are a possible but rarely necessary treatment for severe anemia.

## Gut Health

A healthy intestinal tract is critical in order for your body to effectively absorb and make use of everything you take in through your mouth – food, liquids, and medications. Unfortunately, the intestinal lining can be easily damaged by a variety of diseases and some infections, including HIV. Diarrhea, which can be caused by many things, dramatically affects your body's ability to process foods and drugs.

Uncontrolled diarrhea makes it difficult to absorb nutrients, medications, and fluid. This can be dangerous for your health. *If you have diarrhea five or more times a day, or it lasts more than five days, or you lose more than five pounds*, it's very important to identify the cause and try to correct the problem. To figure out what's causing the diarrhea, your healthcare provider may:

- Assess your medications to see if one or more can cause diarrhea;
- Ask about your diet and possible association with dairy products;
- Collect a stool sample to look for parasites, protozoa, or bacteria;
- Use blood tests to rule out infections that can affect your intestines;
- Check levels of proteins, vitamins, and other important nutrients in your blood to see how diarrhea is affecting them; and/or
- Use a small microscope to look inside your digestive tract (colonoscopy or endoscopy).

With HIV, it's sometimes hard to pinpoint the exact cause of diarrhea. There almost always is a cause, however, so it's important to find out what's going on. If a bacteria or parasite is the culprit, you'll need proper diagnosis, then antibiotics or other types of oral medications depending on the infection. If no infection is found, it becomes particularly important to have other tests performed.

If a medication is causing the diarrhea and it's not possible to change or stop the medication, there are ways to reduce or stop the diarrhea. You can buy anti-diarrhea remedies like Imodium at the drug store or stronger ones by prescription. These seem to work best when taken 30 – 45 minutes before taking the drug that causes the diarrhea. Calcium supplements, fiber supplements, and an amino acid called glutamine can help control diarrhea caused by protease inhibitors like Viracept (nelfinavir) or Kaletra (lopinavir/ritonavir).

Once any infection in the gut is cleared, you'll want to keep your gut healthy. This could include using over-the-counter products like Citrucel or Metamucil to regulate bowel movements or introducing "good" bacteria like lactobacillus to your diet (found in yogurt, but available in greater amounts as acidophilus capsules) to establish a healthier environment in your intestines. Dietary changes that support your gut include: drinking plenty of clean water, eating high-fiber foods like whole

grains (rice, oats, oatmeal, whole grain bread), adding more vegetables and fresh fruits to your diet, and cutting down on caffeine, fried foods, sugar, and animal fat.

## Muscle Mass

There is more benefit to having muscle than just looking good! Muscle provides important fuel for the day-to-day operations of the body. Gaining and maintaining muscle mass is critical to surviving HIV, because muscle helps regulate hormones and helps your body fight infection.



If you lose more than 5% of your weight without trying (7 lbs. for a 140 lb. woman, for example) and can't explain it, get help to figure out what's happening. Many of us are praised and told we look great when we lose weight, but much HIV-related weight loss is often a loss of muscle. Reduced muscle mass can be a sign of wasting, which is linked to faster HIV disease progression. Weight loss is sometimes also part of other changes in body shape and metabolism that need to be monitored.

There is a simple test – called BIA (bioelectrical impedance analysis) – to see if you have healthy levels of overall muscle, fat, and water in your body. To measure the fat or muscle in any one part of your body, you would need a CT scan or DEXA scan. If these tests are not available, it's also possible to measure body dimensions with calipers, a tool that gently pinches flesh at different points on your body. You may want to measure your body composition periodically, since body shape changes aren't always immediately noticeable.

In addition to having a good amount of muscle, it's necessary to get enough calories by eating healthy foods and to drink plenty of water. A combination of resistance exercise (like lifting weights) and aerobic exercise (climbing stairs or swimming) is important, since resistance exercise builds muscle and aerobic exercise burns fat.

As discussed on page 5, low testosterone levels can lead to low muscle mass. Human growth hormone (Serostim) or the anabolic steroids nandrolone (Deca Durabolin) or oxandrolone (Oxandrin) may be alternatives to testosterone for HIV-positive women seeking to restore muscle mass. However, these drugs won't relieve other symptoms associated with low testosterone, including fatigue, low sex drive, or depression. Information exists about the use of anabolic steroids in HIV-positive women – particularly for nandrolone – but we still don't fully understand the long-term risks and benefits. If you're considering using any of these drugs, you may want to talk to other women who've used them and find a healthcare provider willing to explore this option with you. Women using anabolic steroids should have liver function closely monitored.

## Lipodystrophy

Lipodystrophy is the term used to describe a cluster of body shape changes that sometimes occur in people with HIV, especially people taking antiretroviral drugs. It also refers to problems in the way that the body processes fats and sugar. Lipodystrophy has been around almost as long as combination therapy, but, until recently, we haven't had a good definition of it or a clear understanding of how it happens.

One feature of lipodystrophy is an increase in fat in some areas (breasts, belly, and base of the neck) and/or a loss of fat in other areas (face, arms, legs, and butt). Even if your overall body weight stays the same, your body shape can change significantly. Both men and women get lipodystrophy, but women are more likely to have fat gain – particularly in the abdomen and breasts – and men are more likely to have fat loss. *Pay attention to changes in your body and how your clothes fit, and tell your provider about any changes you notice.*

The latest thinking about what causes lipodystrophy is that one class of anti-retroviral drugs, the protease inhibitors (PIs), more often causes fat gain and another, the nucleoside reverse transcriptase inhibitors (NRTIs), more often causes fat loss. We don't have a definitive list of the specific drugs that are most likely to cause lipodystrophy, but Zerit (d4T) is one NRTI that has been repeatedly found to lead to fat loss in many people. Research suggests that other medication-related factors also contribute to the likelihood of developing lipodystrophy, including how long someone has been on treatment. Still other factors may contribute to lipodystrophy, including age, sex, and maybe HIV itself.

There isn't one specific treatment for lipodystrophy. Some research supports switching antiretrovirals to recover fat that has been lost, but the results appear modest. Some people with fat loss in the face have seen improvement with the use of poly-lactic acid injections (Sculptra) or other surgical options. Liposuction has been used to remove fat at the back of the neck (buffalo hump), but it's only a temporary solution because the fat usually returns. Using liposuction to remove fat that has accumulated in the abdominal area is dangerous due to the risk of organ damage. Human growth hormone (Serostim) can help normalize the distribution of fat for some people, but the results are usually short-term and it's expensive.

People with fat accumulation also often experience an increase in fats (lipids) in the blood – especially cholesterol and triglycerides – which can increase the risk of heart disease. Some people also become less able to process glucose, which can lead to diabetes. If you're taking HIV medications, especially a protease inhibitor, it's important to monitor your lipid and glucose levels through regular bloodwork. Lipid levels are best measured in a "fasting state" – at least 10-12 hours after eat-

ing. So a morning blood draw is best. Ideally, have your lipid levels checked before starting antiretroviral therapy and monitored periodically while on treatment.

Some people with high lipid or blood sugar levels address the problem by changing HIV medications, but this may not work and isn't an option for many people. There are medications that help control diabetes and others that lower cholesterol and triglyceride levels. Use of these medications requires a careful look at possible interactions with HIV medications and can cause a new set of side effects.

Three things that you *can* do: eat healthy foods, exercise regularly, and stop smoking. If you're overweight, smoke, don't exercise, and/or are over 40, you're already at higher risk for diabetes and heart disease – with or without HIV. Dietary changes that help keep your heart healthy include: eating less animal fats like butter, cheese, and red meat; adding more fish, especially salmon and sardines, fish oil or flax seed supplements to your diet; and consuming more nuts, whole grain breads, and cereals. Exercise doesn't have to mean joining a gym;



there are many other ways to get your body moving. The important thing is to work towards exercising for 20-30 minutes three to five times a week and to break a sweat while doing so. Women who use oral contraceptives may also want to avoid long-term use of progesterone-dominant ones – they keep estrogen levels low and, over time, can result in increased cholesterol and triglycerides.

## Bone Density Problems

When we're young and growing, our bones get stronger. At some point, perhaps around age 30, we stop building bone. Our bones then get weaker as we get older. Aging women generally experience bone loss at a much higher rate than men, which is closely tied to decreasing levels of estrogen (see "Hormones and HIV" on page 3). Two particular bone conditions have been seen in people with HIV. Osteoporosis (sometimes called brittle bones) is a loss of mineral in bones, making them more porous and more likely to fracture. Osteonecrosis is the death of bone due to a lack of blood supply to the bone. While all the bones can become weak, common sites of fractures are the hip, the spine, and the wrist.

Even without HIV, the risk of losing bone is greater if you are female, over age 50, in or past menopause, white or Asian, slender, and/or have a family history of osteoporosis. Bone loss also happens faster if you smoke, drink alcohol or a lot of caffeine, use corticosteroids like prednisone, don't get enough calcium in your diet, or don't exercise.

People with HIV seem to experience bone loss more often than people without HIV. We don't know whether this is because of HIV disease, its treatments, or a

combination of both. Researchers are looking at individual HIV drugs to determine which ones may accelerate bone loss.

You can have osteoporosis without any noticeable symptoms, but tests can detect the condition. It's very important to be tested if you're at high risk – many women with HIV are – or if you experience bone pain. An X-ray called a DEXA scan is used to measure bone mineral density. It's also important to have your hormone levels checked, since estrogen deficiency can increase the risk of bone loss.

There are several things you can do to slow down bone loss – stop smoking; reduce or stop alcohol and caffeine intake; and increase vitamin D and calcium with supplements and/or by eating foods such as leafy green vegetables and soy-based or dairy products. Regular exercise that requires you to bear weight, such as walking or lifting weights, also helps strengthen your bones.

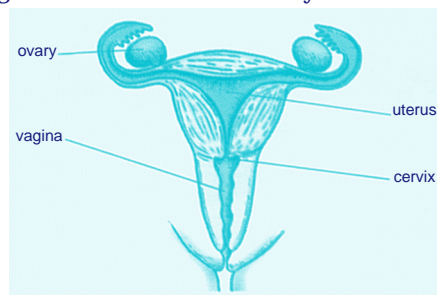
Drugs called bisphosphonates – Fosamax (alendronate) and Actonel (risedronate) – are often used to prevent and treat bone density loss in postmenopausal women. These drugs haven't been studied in pre-menopausal women with bone loss, but some healthcare providers offer them to HIV-positive women with low bone density. Additionally, Evista (raloxifene), a selective estrogen receptor modulator (SERM), may offer bone and heart benefit for women with low estrogen without increasing the risk of breast or endometrial cancer (cancer of the uterine lining).

## GYN Care in HIV

### Finding Good Care

Many women have an HIV provider but don't get good GYN care. One of the most important things we can do for ourselves is find a gynecologist we feel comfortable with. If we don't trust or understand our provider, how can we get answers we can trust? Be sure your gynecologist has experience treating women with HIV. It's okay to ask, "How many women with HIV do you treat?"

You can also talk with other HIV-positive women who feel they get good GYN care and find out where they go. Or call your local infectious disease (ID) clinics – many hospitals have ID clinics that offer specialized GYN services for women with HIV.



Since there's still debate about standards of GYN care in HIV, screening and treatment recommendations for HIV-positive women can vary from clinic to clinic. *It's important to find a provider who knows the different methods used to screen and diagnose GYN conditions seen in HIV.* The next few pages discuss some of the most common GYN problems that affect HIV-positive women.

## Menstrual Problems

Many HIV-positive women report changes in their menstrual cycle, including irregular cycles and more pre-menstrual symptoms. Available research suggests the reasons may have less to do with HIV than other things, but it's important that we pay attention to our periods – especially any changes in the amount of bleeding or pain. The following is a list of some common menstrual changes and things to consider doing if you experience them:

Menstrual Symptom	Possible Causes	What To Do About It?
Lighter bleeding or Missed periods or No periods at all	<ul style="list-style-type: none"> <li>• Pregnancy</li> <li>• Chronic infection like HIV</li> <li>• Malnutrition</li> <li>• Regular heroin, methadone, or amphetamine use</li> <li>• AIDS-related wasting</li> <li>• Steroid use</li> <li>• Menopause</li> <li>• Cysts and other ovarian problems</li> </ul>	<ul style="list-style-type: none"> <li>• Take a pregnancy test.</li> <li>• If you miss two or more periods in a row, get a pelvic exam and blood tests to rule out possible infections.</li> <li>• Check hormone levels.</li> </ul>
Heavy bleeding	<ul style="list-style-type: none"> <li>• Low platelets</li> <li>• Fibroid tumors in the uterus</li> <li>• PID (Pelvic Inflammatory Disease)</li> <li>• Genital tract infection</li> <li>• HIV drugs, such as Norvir (ritonavir), Retrovir (AZT), and others</li> </ul>	<ul style="list-style-type: none"> <li>• Get blood test to check platelet counts.</li> <li>• Review list of drugs and contraceptives you're taking with your health care provider.</li> <li>• Monitor closely for anemia.</li> <li>• Check progesterone levels.</li> <li>• Possibly, get a sonogram.</li> </ul>
Bleeding between periods or Bleeding after sex	<ul style="list-style-type: none"> <li>• Chlamydia</li> <li>• High-grade cervical dysplasia</li> <li>• Problems with the pill</li> <li>• Vaginal tearing from sex</li> <li>• Atrophy (thinning or weakening of vaginal lining)</li> </ul>	<ul style="list-style-type: none"> <li>• Get a pelvic exam and Pap smear.</li> <li>• Get a sonogram or colposcopy to allow your provider to see where the bleeding is coming from.</li> <li>• Check hormone levels.</li> </ul>

Too much blood loss can lead to anemia, so it's important to identify all possible sources of heavy bleeding and try to correct the problem. Heavy bleeding – along with bleeding between periods – may signal an infection in your cervix, vagina, or ovaries. If you have any of the above symptoms, be sure to discuss them with both your GYN *and* HIV medical providers.

### ***Special Considerations for Women Using Birth Control Pills***

In addition to preventing pregnancy, birth control pills (often just called “the pill”) are sometimes used to regulate menstrual cycles or ease symptoms of menopause. The pill comes in many different formulations – some contain progesterone, while others contain both progesterone and estrogen. Every woman responds differently to the pill, and you may need to try several types or doses before you find the best formulation for you.

Some combination birth control pills contain high amounts of ethinyl-estradiol, a synthetic version of the strongest estrogen in your body. The ethinyl-estradiol content of combined pills can range from 20-50mcg. The higher dose formulas can cause side effects in many women and aren't safe if you're over 50. If you use the pill to regulate periods rather than to prevent pregnancy, consider a formulation that contains a lower dose of ethinyl-estradiol.

**Many antiretroviral drugs interact with ethinyl-estradiol, the main ingredient in most birth control pills.** If you're taking Aptivus, Norvir, Kaletra, Viracept, or Viramune, the pill may not work as well because these drugs lower ethinyl-estradiol levels. If you're taking Crixivan, Sustiva, Reyataz, Agenerase, Lexiva or perhaps Rescriptor, you may be getting more ethinyl-estradiol than you need. Most of this information is based on studies in which women took a single antiretroviral with different formulations of the pill for two to four weeks. Since HIV drugs are used in combination, the effect of a given regimen on levels of ethinyl-estradiol can be difficult to assess.

If you're using the pill with HIV drugs that raise or lower ethinyl-estradiol levels, ask your healthcare provider whether you need to alter the dose of the pill. *If your HIV medications lower your contraceptive hormone levels and a dose adjustment isn't possible, you'll need to use condoms or another form of contraception to prevent pregnancy.*

As you can see, there's the potential for drug interactions in almost every HIV treatment decision. That's why it's so important to tell your provider about any medications, methadone, street drugs, herbs, or hormones you're taking along with your HIV regimen. Any time you are prescribed a new medication, be sure to ask your healthcare provider and pharmacist about possible interactions. As part of the drug dispensing service, pharmacies are required to help you identify potential drug interactions. Don't hesitate to use this service.

## Yeast Infections (*Vaginal Candidiasis*)

Your immune system, hormones, and “healthy” bacteria in your vagina all help keep your vagina lubricated and healthy. Changes in your immune status, hormone levels, or the balance between healthy and unhealthy bacteria in your body can result in a range of vaginal symptoms, including yeast infections.

Yeast infections are overgrowths of a fungus called candida, normally found in small amounts throughout your body. When there’s too much candida, your vagina can become irritated or painful. You may experience itching or burning around your vagina or anus and a thick, white vaginal or anal discharge.

Antibiotics, steroids, birth control pills, and foods high in sugar or starch (breads, pastas, and alcohol) all promote the growth of yeast. Douching is not recommended for women with HIV because it reduces levels of healthy bacteria in the vagina that are needed to keep infectious bacteria under control. In women with HIV, recurrent yeast infections are often the result of immune suppression. You’re more likely to develop these infections, or see them come back after treatment, if your CD4 count is going down.

Many women treat yeast infections themselves with over-the-counter anti-fungal creams like Monistat or Gyne-Lotrimin. These creams contain various antifungal agents (like miconazole or clotrimazole) and come in different strengths such as 3% or 5%. They’re used for 3 to 10 days depending on the formulation. Women with HIV often need longer treatment with antifungal drugs or prescription-strength creams. Your provider can recommend the right antifungal and best strength for you.

You may find that some yeast infections just don’t go away or keep coming back after you’ve used a vaginal cream. This is more likely if your CD4s are low, if you use over-the-counter yeast treatments often, or if you don’t use the cream for the recommended number of days. For difficult-to-treat infections, your healthcare provider can prescribe oral antifungal drugs such as Nizoral (ketoconazole), Diflucan (fluconazole), or Sporanox (itraconazole). Keep in mind that, unlike creams, drugs taken orally go through your whole system, can interact with HIV medications, and sometimes cause side effects.

The symptoms of a yeast infection can resemble those of a bacterial infection, which would require different treatment. That’s why it’s a good idea to see your GYN if you notice *any* unusual discharge or odor – especially if you’ve already tried over-the-counter drugs and you’re still having symptoms. Your gynecologist

may collect a sample of your discharge to make sure that it is a yeast infection. A similar vaginal sample can show whether you have healthy levels of acid in your vagina (called vaginal pH). If your pH levels are too high or too low, your health-care provider may suggest simple remedies to help restore a healthier vaginal pH level. This will help prevent infection.

Since HIV can lead to a number of vaginal conditions, consider dietary and other changes that support vaginal health. Dietary changes include less sugar and starch, more soy products, and a multivitamin. If you take antibiotics or birth control pills, you may also want to consider acidophilus supplements to restore levels of healthy bacteria in your vagina. Dry yourself off well after bathing and wear loose, cotton underwear and clothes that won't trap moisture in your vagina. You may also want to steer clear of chemicals (found in scented soaps and detergents) that may cause irritation. Douching isn't necessary for good hygiene and shouldn't be done unless specifically recommended by your provider. Douching can destroy the healthy bacteria in your vagina – bacteria that you need to fight infection.

## Genital Herpes

Many HIV-positive women have genital herpes, a sexually transmitted infection caused by the herpes simplex virus that lives inside nerve cells and causes outbreaks of sores on the skin. You can get genital herpes sores on your labia (vaginal lips), butt, or the area between your vagina and anus.

The herpes virus can be transmitted even when there are no sores present. Transmission occurs through skin-to-skin contact, so condoms only prevent the virus from passing to or from the skin of the penis. If you develop any pain, ulcers, or blister-like sores, see your healthcare provider. To diagnose a herpes infection, your provider may take a small sample of fluid from your sores and try to grow the virus in a culture.

Once you have it, herpes is usually present for life. The body rarely gets rid of the virus, but it can be treated and managed. There are several antiviral medications for herpes, including Zovirax (acyclovir), Valtrex (valacyclovir), and Famvir (famciclovir). Medications taken by mouth are better at controlling herpes than cream and gel forms, but all are available. Medication can heal the sores, reduce the pain, and control outbreaks. People who have frequent or severe outbreaks sometimes choose to take one of the antiviral medications daily to control the disease (called suppressive therapy). This greatly reduces outbreaks and can help prevent transmission of the virus.

For severe and painful sores, your provider can prescribe a lidocaine ointment or

numbing gel. Many women find that applying clay used for facial masks directly to the sores can also help ease the pain.

Herpes outbreaks occur more frequently in HIV-positive women than in women who are HIV-negative. Like other GYN conditions, they can reflect the status of your immune system. If your CD4 count is low or dropping, herpes is more likely to flare up and can be more difficult to treat. Things like stress and sun exposure can also trigger outbreaks. Herpes sores that persist for over one month are linked to severe immune weakness and are an AIDS-defining illness.

## Genital Tract Infections

The vagina, cervix, ovaries, uterus, and fallopian tubes are all part of the genital tract. Most genital tract infections begin in the vagina and are usually easy to treat. Many – but not all – of these infections are sexually transmitted, including chlamydia, gonorrhea, trichomonas (trich), human papilloma virus (HPV), herpes, and syphilis. Condoms can prevent most, but not all, sexually transmitted infections.

If left untreated, simple vaginal infections can progress up your vagina to your cervix, where they may cause inflammation (cervicitis), cellular abnormalities (dysplasia), or both. These conditions are more common in women with HIV, so it's important to seek prompt diagnosis and treatment for *any* symptoms you experience. Some infections don't have early symptoms, but symptoms that you might notice include sores, discharge, pain, or fever. Untreated infections can progress even further up your genital tract to your uterus, ovaries, or fallopian tubes. Here, they can cause pain, inflammation, and fertility problems.

*PID (pelvic inflammatory disease)* is a general term that refers to inflammation somewhere in your upper genital tract. It usually begins with easy-to-treat infections like chlamydia or gonorrhea. Though no more common in HIV-positive women, PID can be very serious and cause long-term damage if it occurs. The best way to prevent PID is to have regular GYN exams every six months, especially since some sexually transmitted infections don't have noticeable early symptoms. Go in right away if you have any of the following symptoms: ongoing belly and/or lower back pain; irregular periods; abnormal bleeding; cervical tenderness (during sex or on exam); painful urination; abnormal vaginal discharge; or chills and fever.

*Even if you don't have any symptoms*, regular and thorough GYN exams are particularly important for HIV-positive women.

If you're having sex, at least one physical exam a year should include a pelvic exam; a cervical swab (different from a Pap smear) for chlamydia, gonorrhea, and other common infections; and a blood test to check for syphilis. Other things to consider:

- A simple vaginal sample can identify yeast and bacterial levels in the vagina and measure your vaginal pH.
- Pap smears only detect cervical abnormalities. If you're having problems higher or lower in your genital tract, you may need a combination of blood test, cultures, pelvic exam, sonogram, colposcopy, or biopsy to diagnose the problem.
- If you have ever had genital warts, anal sex, or have HPV, it's important to have:
  - A Pap smear every six months – sooner if results show abnormal cells.
  - A rectal (butt) exam to check for warts in the anus.
  - An anal Pap smear to check for abnormal anal cells.
- You can be protected from Hepatitis A and Hepatitis B with simple vaccinations. If you haven't been vaccinated, ask your healthcare provider about this simple series of shots.

## HPV and Cervical Dysplasia

HPV (human papilloma virus) is the most common sexually transmitted infection. There are over 100 strains of HPV, and it's possible to have more than one strain at the same time. Most women are infected with at least one strain of HPV during their lifetime, but often don't know it.

For women who *don't* have HPV, the best protection is the use of condoms or other barriers, since HPV can be passed from the mouth to the genital region. Researchers are working on a vaccine to prevent HPV transmission, and promising results have recently been reported, but these vaccines aren't likely to help those of us who already have HPV infection.

Some HPV strains cause warts to develop on the skin, mouth, and genital area. Other strains infect cells inside the cervix, vagina, or anal canal where they can cause lesions to develop. Lesions are areas of abnormal tissue. If left untreated, lesions can lead to abnormalities in the tissue of the cervix, anus/rectum, vagina, and vulva. Cell abnormalities are called dysplasia, which means that the cells are abnormal in size, shape, or appearance. These abnormalities can lead to cancer in some women.

In addition to having higher rates of HPV infection than HIV-negative women, HIV-positive women who get HPV are more likely to have:

- Chronic HPV infection
- Infection with the HPV strains that are more likely to cause cancer
- HPV in both the cervix *and* anus
- Several strains of HPV at once
- Reactivation of an HPV infection that was previously under control.

Any of these factors can make us more likely to develop cervical and anal disease. Immune suppression from HIV also plays a role. It seems that with lower CD4 counts and higher viral loads, we're at increasing risk for developing HPV-related lesions – including pre-cancerous lesions – in the cervix and anus.

Untreated sexually transmitted infections, especially chlamydia, can make your cervix more vulnerable to damage from HPV and other infections. So can smoking. Low levels of certain nutrients (including beta-carotene, folic acid, and vitamins A and C) can also make the cervix more vulnerable. It's not clear whether taking extra amounts of these nutrients helps, but if you have HPV, it's at least a good idea to maintain healthy levels of these nutrients, either through food sources or a multivitamin.

## Screening Methods

*Pap smears* are the first step in screening for abnormal cell changes in the cervix and the anus. Pap smears collect surface cells – called squamous cells – from the area of your cervix or anus most likely to show damage caused by HPV. Pap smears can detect inflammation and, in most cases, predict cervical or anal cell abnormalities. The traditional Pap test can miss abnormal cells. This makes it particularly important to be screened on a regular basis. New liquid-based preparations (ThinPrep, AutoCyte PREP) generally appear to be more sensitive.

As an HIV-positive woman, you may need more frequent screening than a woman who doesn't have HIV. How frequently depends on a lot of individual factors, including the results of your previous Pap smear, whether you've been treated for warts or other abnormalities, and the state of your immune system. If your CD4 count is below 250 or your CD4 count is above 250 but has been dropping, have a Pap smear at least every six months. For women with HIV, *any Pap smear result showing abnormal cells must be further evaluated by colposcopy.*

*Colposcopy* is an exam of the cervix using a low-powered microscope to look at the tissue more closely. It allows your healthcare provider to see a magnified portion of your cervix and identify any areas of abnormal tissue, such as lesions, warts, and inflammation. A limitation is that colposcopy can't distinguish well between mildly abnormal tissue (low-grade lesions) and abnormal tissue that is more likely to progress to cancer (medium to high-grade lesions). If lesions are seen during colposcopy, they are often examined by biopsy.

*Biopsy* is a procedure that removes and examines a small tissue sample from your cervix. Biopsy is the most reliable way to tell the difference between low-grade and high-grade lesions. Biopsy is important for diagnosis, but it can be uncomfortable, even painful, and some women have mild bleeding afterward. If you need a biopsy, ask your provider about pain management options during the visit *before* the procedure.

Many HIV-positive women need more than one biopsy as part of diagnosis or follow-up care. Understandably, this can make it hard to go back. But it's important to stay involved in your care and have input into treatment decisions that affect you. If you need repeated biopsies and find yourself feeling resentful, angry, or scared, tell your gynecologist. Remember – your GYN wants to keep you healthy. The more your providers know about what's going on with you, the better they'll be able to care for you.

### What Do Pap Test Results Mean?

If you've had an abnormal Pap smear, you may recognize the terms LSIL, CIN, HSIL, or dysplasia. These are some terms from the many different systems used to classify cervical and anal tissue abnormalities. Most U.S. labs use the Bethesda System to report Pap smear results. The system includes information about the sample (satisfactory, limited, unsatisfactory) and classifies cell abnormalities according to the following categories:

- Negative for squamous intraepithelial lesions (SILs) or dysplasia  
*No changes in size and shape of cells were seen. The cells in the smear appear normal.*
- ASCUS – atypical squamous cells of undetermined significance; or ASC-H – atypical squamous cells, can't rule out high-grade lesions (HSILs)  
*ASCUS and ASC-H are cells that can't be classified as completely normal or abnormal. ASCUS may indicate you have inflammation in your cervix. ASC-H is a category that was added in May of 2002. If you get either of these results, you should have a colposcopy to rule out high-grade abnormalities.*
- LSIL – low-grade squamous intraepithelial lesion  
*LSIL means there are abnormal cells on the surface of your cervix. This category can be broken down further into HPV infection and CIN I. CIN stands for cervical intraepithelial neoplasia; the "I" indicates severity (I, II or III). LSIL is not considered a serious abnormality, but it needs to be watched carefully. At this time, treatment is **not** considered standard for HIV-positive women with LSIL.*
- HSIL – high-grade squamous intraepithelial lesion  
*HSIL is a more severe abnormality, with a higher likelihood of progressing to*

*cancer. HSIL can be further broken down into CIN II or III. Any high-grade lesion in your cervix, vagina, or anus requires treatment.*

- Invasive cancer

*Stage I: confined to the cervix.*

*Stage II: extends beyond the cervix but not to the pelvic wall; may include upper vagina involvement.*

*Stage III: extends to either the lower third of the vagina or the pelvic wall.*

*Stage IV: extends beyond the pelvis to nearby organs, such as the bladder or rectum or to organs beyond the pelvic area, such as the lungs, liver, or bone.*

### Screening and Treatment Guidelines for HIV+ Women

Various sets of screening recommendations exist for HIV-positive women, and there is not complete agreement about what the standard of care should be. Recommendations for women with HIV are generally more aggressive than those for HIV-negative women. They urge Pap smears more often and colposcopy (with possible biopsy) anytime ASCUS or other abnormalities are found. The following chart is adapted from the Bethesda System and incorporates some of the various screening recommendations for women with HIV.

<b>If Pap smear shows:</b>	<b>Then:</b>
Negative	Pap smear in 6 months to a year.*
ASCUS or ASC-H	Colposcopy to investigate; Treat any source of inflammation; Follow-up Pap smear in 3-8 months.*
LSIL	Colposcopy plus biopsy; Repeat Pap smear in 3-8 months.*
HSIL	Colposcopy plus biopsy to determine degree of lesions, followed by treatment; Repeat Pap smear in 4-6 months.*
Carcinoma in Situ (precancerous condition) or invasive cancer	Immediate treatment, plus frequent follow-up through Pap smear and colposcopy to prevent recurrences.

\* Depending on CD4 count

### Treatment Options for Dysplasia

For those of us with HPV, the best way to prevent damage from the virus is to be screened carefully and regularly for changes in the cervix and anus, and then to treat any high-grade abnormalities so that they don't progress to cancer.

Treatments for HPV can remove genital warts, HPV lesions, and abnormal tissue. Genital warts can be treated with topical solutions or by laser, freezing, or burning. Dysplasia treatments focus on destroying the abnormal tissue so that it doesn't progress to cancer. Treatment options include:

- LEEP (loop electrosurgical excision procedure): removes abnormal tissue with an electric scalpel.
- Cone biopsy: removes a cone-shaped piece of tissue from the cervix by surgery or laser. This is done under anesthesia. It's frequently used to treat high-grade dysplasia in HIV-positive women.
- Electrocautery (burning).
- Topical solutions.

The specific treatment for dysplasia depends on the grade and severity. Cryotherapy uses liquid nitrogen to destroy the abnormal tissue by freezing it and is *not* recommended for women with HIV. Women who have been treated with cryotherapy in the past should be closely monitored due to a higher rate of dysplasia recurrence.

There are additional challenges to treating cervical and anal abnormalities in HIV-positive women:

- Many respond poorly to standard therapies used to treat HSIL.
- Some need multiple treatments using different methods.
- Treatment of HSIL can only try to manage HPV – it won't prevent a recurrence.
- There is low success treating LSIL.
- Anal and cervical dysplasia and cancer are more common in HIV-positive women.

Both cervical and anal dysplasia can return after treatment. Recurrences may be more likely if you have a higher viral load or aren't on antiretrovirals, but it's not clear that antiretroviral therapy slows the progression of cervical disease. Even when the immune system is partially restored by anti-HIV treatment, anal and cervical dysplasia may progress to cancer. Careful, regular monitoring is the best way to ensure that any problems are detected early and treated as soon as possible.

## Anal HPV and Anal Dysplasia

Anal HPV is common in women with HIV, especially women who've had genital warts, cervical dysplasia, or anal sex. Although anal sex is the most direct way to get anal HPV, you can have anal HPV even if you've never had anal sex. One large study (the Women's Interagency HIV Study) found that 70% of the HIV-positive women studied had anal HPV. Using anal Pap smears, abnormal cells were found in 42% of the women with CD4 counts less than 200 and 25% of the women with CD4 counts between 200 and 500.

*If you have HPV, have ever had cervical dysplasia, or have had anal sex, ask your healthcare provider for an anal exam and an **anal Pap smear** to check for anal HPV.* Anal Paps are like cervical Paps, but they collect and examine cell tissue from the anus. If ASCUS, ASC-H, or any other abnormalities are found, your provider can refer you to a specialist for an anoscopy (similar to a colposcopy for the cervix), which looks inside your anal canal and identifies any lesions, warts, or abnormal tissue that might need treatment.

Recommendations comparable to those for vaginal HPV don't exist yet for anal HPV, but the field is advancing and we may soon see more guidance about how to incorporate this into routine primary/GYN care for men and women with HIV.

As HIV-positive women, it's important that we are evaluated regularly for cervical and anal HPV. Many providers have no experience with anal Pap smears. If our healthcare providers are unskilled at performing anal Pap smears, we need to encourage them to be trained and become skilled with anal screening. **If they refuse, we should insist on being seen by providers who *can* perform these necessary evaluations.** Such providers exist, and anal pap smears are increasingly becoming part of care for HIV-positive people with anal HPV infection. If we demand it, important medical procedures like anal screening will become routine components of our HIV care.

## Conclusion

For many women, HIV is just one of many daily struggles. Poverty, addiction, and violence are common. While we often talk about physical health in HIV, we rarely talk about the grief, loss, fear, and isolation so many HIV-positive women feel at one point or another. Without support, these feelings can be overwhelming. Regardless of where you're at, we encourage you to reach out and find support wherever you can. In addition to learning as much as possible about HIV, treatment options, and the physical conditions discussed in this booklet, it's important to take care of yourself mentally and emotionally.

We encourage all women reading this booklet to reach out to other women with HIV and people in your life who support you. Most importantly, keep asking questions of your healthcare providers, other people with HIV, treatment educators, whomever! The more you know, the better you'll be able to advocate for yourself and other people living with HIV.

There are lots of unanswered questions about HIV, especially for women, and no one answer about the best way to treat it or live with it. Until we have better answers, we need to keep pressuring research institutions, industry, healthcare providers, activists, and our own organizations to take an active interest in our experience.

# Resources

## FREE INFORMATION & ORGANIZATIONS FOR HIV-POSITIVE WOMEN

**Babes Network** *BABES newsletter* (English & Spanish)  
(206) 720-5566 or write 1120 E. Terrace St., Seattle, WA 98122

**NJWAN: New Jersey Women and AIDS Network** Sister Connect Hotline (800) 747-1108 [www.njwan.org](http://www.njwan.org)

*Positive? how are you feeling?* brochure for women. [www.projinf.org/pub/ww/bridge.html](http://www.projinf.org/pub/ww/bridge.html)  
Call Project Inform (800) 822-7422

**The Well Project** [www.thewellproject.org](http://www.thewellproject.org)  
Email address and password required to access full site; information about HIV issues relating to women;  
bi-monthly email newsletter. (434) 293-2955

**Women Alive** Los Angeles, CA (323) 965-1564 Hotline: (800) 554-4876 [www.women-alive.org](http://www.women-alive.org)  
Treatment information, supportive services, & lots of links; newsletter available by mail.

**WORLD: Women Organized to Respond to Life Threatening Diseases** Oakland, CA  
Treatment information (particularly about pregnancy), advocacy, news, and HIV University;  
*WORLD* newsletter by & for HIV+ women and their loved ones. (510) 986-0340 (Bilingual)

## ONLINE SOURCES OF TREATMENT INFORMATION

**AIDS Community Research Initiative of America (ACRIA)** [www.acria.org](http://www.acria.org)  
Free brochures in English & Spanish and quarterly treatment publication, *ACRIA Update*. Call (212) 924-3934 ext.120 or order online.

**AIDS Nutrition Services Alliance (ANSA)** [www.aidsnutrition.org](http://www.aidsnutrition.org)  
Fact sheets on nutrition and HIV and links to other nutrition sites.

**AIDSinfo** *Guidelines for the Use of Antiretroviral Agents* [www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov)

**AIDSmap** [www.aidsmap.com](http://www.aidsmap.com) Detailed information about the immune system, current and investigational antiretrovirals, opportunistic infections, prevention, and lots of information about women & HIV.

**AIDSmeds.com** Treatment information & news, question & answer forums. [www.aidsmeds.com](http://www.aidsmeds.com)

**The Body** [www.thebody.com](http://www.thebody.com) Site offering treatment materials from a variety of sources. Check out the women's section: [www.thebody.com/features/women](http://www.thebody.com/features/women)

**Hepatitis C Support Project, HCV Advocate** [www.hcvadvocate.org](http://www.hcvadvocate.org)  
Information & support for people with hepatitis C/HIV and hepatitis B/HIV co-infections.

**National Center for Complementary and Alternative Medicine (NCCAM)** [www.nccam.nih.gov](http://www.nccam.nih.gov)  
Not HIV-specific; info about complementary and alternative therapies & clinical trials studying these therapies. (888) 644-6226; TYY/TDY: (888) 464-3615.

**New Mexico AIDS InfoNet** Fact sheets in English & Spanish & lots of links. [www.aidsinfonet.org](http://www.aidsinfonet.org)

**Project Inform** [www.projectinform.org](http://www.projectinform.org)  
Lots of HIV treatment information: newsletters; fact sheets and articles by topic; and literature specific to women, in English and Spanish. National treatment hotline (English & Spanish): (800) 822-7422

Visit [www.acria.org](http://www.acria.org) for a reference list of sources used to create this brochure as well as additional sources pertaining to women and HIV.



ACRIA is an independent, non-profit community-based AIDS research and education organization committed to improving the length and quality of life for people living with HIV/AIDS through medical research and treatment education.

ACRIA conducts a free Treatment Education Program to offer people living with HIV/AIDS the tools and information to make informed treatment decisions. Education program services include: workshops conducted at community-based groups throughout the New York City area in English and Spanish; technical assistance trainings for staff of AIDS service organizations; individual treatment counseling; and publications, including our quarterly treatment periodical, *ACRIA Update*, and brochures in English and Spanish on treatment-related topics. TrialSearch is our online, searchable database of HIV clinical trials enrolling throughout the United States. ACRIA's National HIV Treatment Education Technical Assistance Program offers ongoing support to help non-medical service providers and community members in various parts of the country acquire the skills and information needed to provide HIV treatment education in their communities.

To learn more about ACRIA's research studies or the Treatment Education Program, please call or write. Information about our programs and copies of *ACRIA Update* and our brochures are also available on our website.

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AIDS Community Research Initiative of America  
230 West 38th Street, 17th Floor, New York, NY 10018  
[www.acria.org](http://www.acria.org)

J Daniel Stricker, *Executive Director*

