DEC 1999 ISSUE 5

WISE *words*

HIV/AIDS TREATMENT INFORMATION AND ADVOCACY FOR WOMEN

A Word from WISE

This past October, over 2,700 people from the Americas gathered in Los Angeles for the 1999 National Conference on Women and HIV/AIDS. In an epidemic that has too often left women invisible, it was extraordinary that nearly 1,000 conference participants were women living with HIV. We dedicate this issue of *WISE Words* to selected highlights of this important conference.

Participants exchanged information on new research and personal experiences on a broad range of issues. Among the presentations were more findings on biologic differences in the way HIV causes disease and how the immune system resists HIV. Promising data on preventing mother-to-child HIV transmission were also presented. Much discussion occurred about drug side effects and body shape changes.

While the presentations were generally informative, many participants noted communication gaps between women living with HIV/activists and scientists/care providers. Presentations often focused on the growing state of knowledge regarding women and HIV, but often without regard to the practical issues positive women face right now. Although at times, these gaps frustrated both sides, they still served as a powerful reminder of the need to forge a common language among us all.

Angela Garcia

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Highlights from the 1999 National Conference on Women and HIV/AIDS

Living with Side Effects

Drug side effects were a huge area of concern among women at the recent Women and HIV/AIDS Conference. Many described their ongoing struggle with side effects and the negative impact of side effects on their lives. Others described unsympathetic attitudes from healthcare providers with regard to complaints of drug side effects.

Side effects can be serious. They can impact day-to-day living. They can be dangerous and negatively affect one's ability to stay on drugs properly. This last point was made especially clear by many women's stories of self-prescribed dosing and self-dose reduction. As one woman who self-dosed without her doctor's knowledge said: "There's my doctor's dose, and then there's my dose. My dose is the only thing that works for me . . . cutting it in half is the only way I can stand the pills."

While her reasoning may sound appealing, self-dosing is dangerous. Self-dosing and dose reduction are recipes for speeding the development of drug resistance. Changing your regimen without your provider's knowledge and instruction can cause a lot more trouble in the long run than dealing with the side effects themselves.

Learning about side effects and how to best manage them and talking with your provider about what you're experiencing will keep you healthier, longer.

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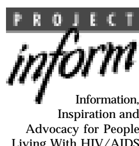

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Living With Side Effects, continued

Because this is such an important issue, the entire next issue of *WISE Words* will be dedicated to side effects and their management. A sample of the issues discussed at the conference follows.

Treating Anemia

Anemia* is a common and sometimes serious condition associated with HIV and with some therapies used to treat HIV. Anemia is a significant reduction in the level of red blood cells that carry oxygen throughout the body. Doctors measure these cells during blood tests as a part of routine monitoring of HIV disease. Symptoms of anemia can include weakness, fatigue, depression, loss of sex drive and menstrual irregularities. Anemia may also quicken HIV disease progression.

Know your viral load, CD4+ cell count and hemoglobin count.

A new study shows that epoetin alfa (Epogen®, Procrit®) is useful in treating mild-to-moderate anemia in women living with HIV. Epoetin alfa had been shown effective in treating HIV and HIV drug-related anemias for HIV-positive people in general. The new study proves this point is equally true in women.

Epoetin alfa was effective in treating AZT-related anemia, as well as anemia related to HIV or other anti-HIV drugs. Women in the study received epoetin alfa once a week by injection for eight weeks. Overall, the drug was well tolerated with minor side effects, including body aches, nausea and fever.

*Note: Among positive women, anemia is independently connected with high viral load (over 50,000 copies) and low CD4+ cell count (less than 200 cells). Anemia is also linked with the use of AZT (zidovuidine, Retrovir®), African American race and a MCV count less than 80 (mean corpuscular volume, a measure of red blood cells).

***Bottom Line:** know your viral load, CD4+ cell count and hemoglobin count. When you consider starting or switching anti-HIV therapy, think about your risk for developing anemia and take into consideration drugs linked to anemia.*

A Rash of Rash

Rash appears slightly more often among women taking nevirapine (Viramune®) than men (12% vs. 8%, respectively). However, women who experience rash appear more likely to have a severe or life-threatening rash than men. The reason for the difference is unknown, but many believe it may be due to higher blood levels of nevirapine in women.

On a similar note, the study reported that women more likely have a rash from nelfinavir (Viracept®) than men (5% vs. less than 2%, respectively). Talk to your doctor if you're starting a drug which may cause rash and learn how to monitor for its early signs. Keep medications like Benadryl on hand to manage the rash it should appear. If you experience a rash, call your provider immed iately.

Having Trouble with Ritonavir (Norvir®)?

Well, you're not alone. A recent study reports that the majority of women (66%) cannot tolerate a full dose of the drug. The most common reported side effects include nausea, vomiting, diarrhea, cramping and tingling and numbness around the mouth (called oral parathesia). Reports from another study (not presented at the Conference) included excessive menstrual bleeding. Such side effects are linked with higher than necessary blood levels of ritonavir and may signal the need to discontinue the drug.

The Insulin-Menstruation Connection

According to a new study, factors that contribute to *lipodystrophy* may affect menstrual cycles as well as body shape and lipid levels (fats like triglyceride and cholesterol). The study reports that women with increased lipid levels are more likely to have amenorrhea, which is the absence of menstruation. In addition, women with increased lipids are more likely to have abnormal fat accumulation around the gut. Similarly, women with these body shape changes are more likely to have amenorrhea.

Menstrual irregularities are also associated with HIV disease itself and may not always be directly related to insulin levels. More information regarding the insulin, menstruation and body shape changes is expected soon.

* Note: Lipodystrophy is currently a catch-all term. It's used to refer to certain changes in body shape and changes in lab results that reflect the way the body processes fats, sugars and proteins.

The Dangers of Lactic Acidosis

Lactic acidosis is a life-threatening condition caused by high acid levels in the blood. It's also associated with the development of liver disease. While lactic acidosis is relatively rare, an unusually high percentage of the reported cases have been in women. Half of the women that developed lactic acidosis were considered overweight (over 175 pounds).

Lactic acidosis has long been linked to the use of anti-HIV therapy, specifically the nucleoside analogue reverse transcriptase inhibitors (NARTIs). Have your lactate levels checked quarterly to determine your risk for developing this condition. Anecdotal reports suggest that some vitamins such as coenzyme Q10 may prevent lactic acidosis, but they need to be confirmed in studies.

More on Gender and Disease Progression

More data are becoming available that support earlier reports of gender differences in viral load (*WISE Words #3*). In addition, two new findings that add dimension to this emerging picture were presented at the recent Women and AIDS conference.

First, women with a history of injection drug use had significantly lower viral levels than women who hadn't used injection drugs. More research is needed to determine the cause of this difference. It could be due to a variety of factors, including (but not limited to) issues around modes of HIV infection (e.g. sexually or directly into the blood through the vein) or lifestyle factors linked to a history of intravenous drug use.

Second, when comparing race-ethnic groups within the study, women of color had significantly lower viral loads than white women. These findings are contrary to another study that found viral loads among African Americans were higher than whites. Nevertheless, the possibility of racial or ethnic differences in viral load and disease progression may exist and it needs further study.

Do Women Respond Better to Anti-HIV Therapy?

Another study reports there may be gender differences in CD4+ cell count responses after beginning combination anti-HIV therapy. In this study, after eight months of therapy, the average increase in CD4+ cell count was greater among women than men (34% vs. 26% increase). These results were not explained by either CD4+ cell counts or viral loads at start of therapy. Further study is needed to determine if immune recovery (noted by increased CD4+ cell count) is different between women and men.

Do Hormonal Contraceptives Affect Viral Levels?

Hormonal contraceptives do not appear to affect viral load in women, according to the Women's Interagency HIV Study. The study compared HIV levels in women using hormonal contraceptives (i.e. oral contraceptives, injectable Depo-Provera® or Norplant®) to women not taking them. After 20 months, no differences were found between the two groups. In addition, there was no connection between viral load changes and the type of hormonal contraception used.

These results may ease some women's concerns about using hormonal contraceptives. But, unanswered questions still remain about the interaction of hormonal contraceptives with particular anti-HIV therapies and HIV disease itself.

Testosterone Therapy in Women with Wasting, Loss of Periods

Women naturally produce testosterone. However, women with AIDS-related wasting (weight loss without a clear cause) have lower than normal levels of it. A break or decline in the frequency of menstruation is one of many symptoms connected with AIDS wasting in women.

Results from one study suggest that women who receive a replacement dose of testosterone (a dose that brings the hormone to a normal level in blood) experienced weight gain, return of menstruation and improved quality of life. Testosterone replacement was well-tolerated and no negative effects occurred on lipid levels or liver function tests. However, more studies are needed to measure the effects and safety of testosterone use in HIV-infected women, particularly as a possible means to manage lipodystrophy and menstrual disorders.

Unique Issues Among Older Women

An increasing number of "older women" are becoming infected with HIV. At the same time, with better strategies for HIV care (including anti-HIV treatments), women are living longer, healthier lives.

An important presentation at the conference discussed the unique issues of older women (defined as over 45) living with HIV. Some of these issues are physical conditions common among older people in general. These include high blood pressure, arthritis, diabetes, osteoporosis, heart and liver disease, and cancer.

Woman-centered care settings should not be viewed as an impossible ideal but as the goal for which we all need to advocate.

Women over 45 should remind their doctors about age-appropriate health screening. Doctors can sometimes be so focused on treating and managing HIV that they forget to deliver age-appropriate health screening that includes monitoring for all the conditions noted above.

Depression is also a common issue among older women. While obvious psychological and social factors can increase rates of depression among positive older women (including fear of disclosure and loneliness), there may also be a physiologic basis for depression.

After menopause, women produce less of the chemical serotonin. Low levels of this chemical are associated with depression, though this doesn't necessarily mean that low levels *cause* depression. Hormone-replacement therapy may lessen incidence of depression by raising serotonin levels. However, more studies are needed to determine if this is a direct benefit of hormone-replacement therapy.

Odds and Ends

Benefits of Resistance Testing During Pregnancy

The usefulness of resistance tests for HIV-positive pregnant women may outweigh their drawbacks. Resistance testing—a way of measuring which drugs a person's HIV is likely to beresistant to—is already recommended for pregnant women who haven't been on anti-HIV therapy. It's being proposed that all pregnant women with viral loads above 1,000 copies/ml should have resistance testing, even if they were or already are taking anti-HIV therapy at the time of pregnancy.

The current rate of drug resistance among pregnant women supports the use of resistance testing. Presence of drug resistance while taking anti-HIV therapy heightens the likelihood of increasing viral load. During pregnancy, this could then increase the risk of transmitting HIV—and even a drug-resistant strain—to the newborn. Presence of drug resistance would call for the use of treatment with a different regimen to which HIV is sensitive, thereby providing more potent anti-HIV activity to the mother and helping to prevent mother-to-child HIV transmission.

> Sometimes doctors can be so focused on treating and managing HIV that . . . women over 45 should remind them about age-appropriate screening.

The recommendation that pregnant women receive resistance testing reflects the current standard of individualized HIV care for pregnant women. It supports the need to develop the most active and effective anti-HIV treatment regimens for both mother and baby.

Determining which drugs no longer work, or do not work maximally, will help in this regard. This must include determining whether AZT, which is currently recommended as a component for all pregnant women's anti-HIV regimens, remains an effective and warranted drug option in each case.

Women in Control: An Update on Topical Microbicides

Topical microbicides are designed to kill, block and/or neutralize bacteria and virus before they enter the body or infect cells. They're currently being studied as a woman-controlled method for preventing HIV and other sexually transmitted diseases (STDs). Microbicides may be used as creams, gels, vaginal suppositories or vaginal rings. Ideally, they would be long-acting and applied hours before sex without being messy or irritating.

If these products prove effective, women living with HIV may use them two different ways. The first would be to prevent sexual transmission to their partners (and prevent themselves from getting an STD). The second would be as a vaginal wash during pregnancy that may prevent passing HIV from a mother to her child. The vaginal wash could be used along with currently approved methods to further decrease the risk of mother-to-child transmission.

Currently, 23 microbicides are being studied and 50 more are being developed. Researchers hope the first microbicides will be available in the next few years.

Yes to Woman-Centered Care!

Why do many women living with HIV still have unmet medical needs? A recent study of women's medical services in five cities found several factors that result in uneven medical access for women. The most important factor was women's family obligations. In other words, many women look after their family's health *before* taking care of themselves.

Woman-centered care *is* family-centered care because focusing on women often includes focusing on family health. When asked about the type of care they need, women noted the following important points:

- a comfortable, safe atmosphere that feels homey,
- transportation to and from services,
- childcare on site, and
- help with food and housing, and getting several services in one place.

Current woman-centered services report increases in the well-being of their clients. The study concludes that woman-centered care settings should not be viewed as an impossible ideal but as the goal for which we all need to advocate.

Adherence to Therapy: Are Women Different?

Adherence to therapy means taking your drugs according to the dose and timing prescribed. Studies show there's no real difference (based on gender alone) between women and men adhering to therapy regimens.

When asked about missing doses of medication in the last three days, there was little difference between the number of women vs. men who missed a dose. The same was true for doses missed in the last day. In general, however, neither men nor women, as groups, showed very good adherence habits.

Women with children did not fare quite as well, however. Overall, the study showed that women with two or more kids may have many more barriers to adherence than women with fewer or no kids.

Adherence to medication is an ongoing process. Studies show that a doctor's ability and willingness to work with a patient can impact one's ability to stay on a demanding drug schedule. It's important for women to get the help and support they need today for proper adherence tomorrow. A good plan for adherence begins with a wise choice of therapy, one with which a woman believes she can cope.

Hepatitis C Virus (HCV) & HIV

Several workshops discussed HIV and Hepatitis C virus (HCV) infection in women (HIV/HCV co-infection). In most people, HCV infection becomes chronic (on-going). Over long periods of time, chronic infection with HCV can lead to life-threatening liver disease and liver cancer. This can occur in people living with either HIV/HCV or HCV alone.

HCV and Liver Disease

Because we don't yet have long-term studies of the outcome of HCV, it's not possible to estimate the percent of people who will develop serious liver disease over their lifetimes. Researchers fear that the high chronic infection rate signals a more troubling long term forecast when HIV and HCV are present together. Studies have shown that people with HIV and HCV appear to develop early stage liver disease more rapidly than HIV-negative people. This increase hints at a worsened overall outlook for people living with HIV and HCV.

What Treatments Are Available?

Treatment for HCV exists, but there's controversy over when to use it and who might best benefit. The current standard of treatment uses a combination therapy that includes an interferon-alpha (an injectable drug) and ribavirin. This combination produces better results than interferon alone, which was the earlier standard.

Both anti-HCV drugs have potential side effects. Interferon-alpha side effects include moderate to severe flu-like symptoms. Ribavirin can cause a decrease in red blood cells, called anemia (see page 2 for more on anemia). Since ribavirin can also cause birth defects, it should not be used during pregnancy. Women and men using ribavirin are advised to wait at least six months after ending therapy before trying to have children. Depression is another condition to be aware of though it can be confusing whether depression is a side effect of anti-HCV therapy or a symptom of HCV itself.

When to Start Treatment

When to start treatment is even more controversial in HCV than it is in HIV. If liver function tests (LFTs) are consistently three to five times the "normal" range, discuss with your doctor the possible causes of the higher LFT values. See whether other tests, such as a liver biopsy, might be justified to help determine the need for anti-HCV therapy. Currently, liver biopsy results are regarded as the best way to decide when to start HCV therapy.

Although viral load tests for HCV are also available, it's unclear how to best use the results of this test in making treatment decisions. Also, before starting therapy, it can be valuable to take a test to determine which "type" of HCV you have. Though people with HCV type 1 (the most common in the US) are least likely to benefit from current anti-HCV therapy, some can still benefit from treatment. Speak with your doctor about what your liver biopsy, viral load tests and HCV type mean for you and your health.

Treatment Decisions

HCV treatment poses many challenges to someone living with HIV and HCV. Some people may find it hard to integrate anti-HCV therapy into their lives, particularly if they are also taking anti HIV therapy. The significant side effects of anti-HCV therapy can make family and work life difficult without assistance. People with HIV and HCV may also choose not to treat HCV because the success rate of therapy is low and the course of treatment long (48 weeks). This is particularly the case in people with HCV type 1.

Some providers have biases against HCV treatment for a person with a history of substance use/abuse. The ritual of injecting anti-HCV drugs, coupled with the potential side effect or occurrence of depression, may trigger relapses in substance use/abuse. People considering anti-HCV therapy should discuss this with their providers and people they trust.

Comments

There's a dire need for studies to better understand HIV and HCV co-infection. Some studies shows that women are more likely to benefit from anti-HCV therapy then men. However, other studies show that African Americans may fare less well than whites. It is unknown whether this is the case for African American women.

Caring for Your Liver

HEPATITIS C VIRUS & HIV

- Avoid/decrease alcohol intake
- Decrease the use of ibuprofen (Advil®, Motrin®), acetaminophen (Tylenol®)
- Eat healthy, low(er) fat foods
- Add a multi-vitamin
- Explore herbal therapies, like burdock and milk thistle
- Get plenty of rest

More effective and less toxic therapies are needed. If you're co-infected with HIV and HCV, seek out a doctor who's knowledgeable about both viruses, if possible. For more information about HCV treatment, call the Project Inform Hotline and ask for the Hepatitis Fact Sheet. Also, in a future issue of WISE words, HIV/HCV co-infection treatment issues will be discussed further—so stay tuned.

HIV/AIDS Policy Discussions

Many well-attended public policy workshops were held at this year's Women and HIV Conference. They provided opportunities for participants to share organizing strategies and discuss important federal, state and local policy issues. The following are selected highlights.

HIV Testing of Pregnant Women and Newborns

This subject has been debated for many years. It has gained momentum recently as elected officials, providers and advocates debate the need for a new HIV testing policy for pregnant women. Many conference participants weren't aware of these debates, but became more interested with getting involved in advocacy around this issue.

We'll find a pull quote and put it here. But rest assured, there will be a pull quote placed here to make the layout of this publication a little more interesting.

In 1997, New York started the first mandatory HIV testing program of newborns and mothers in the United States. The HIV Law Project in New York has collected information about the effects of this legislation and has documented some disturbing trends. These include violations of confidentiality, lack of adequate pre- and post-test counseling and delays in receiving tests results.

The implementation of the testing program has not resulted in any measurable reduction in mother-to-child transmission of HIV. Therefore this legislation, without having necessary safeguards and provider education, not only violates the rights of women but also appears unsuccessful in its stated goal of protecting babies from HIV infection.

In 1996, amendments were added to the Ryan White CARE Act paving the way toward mandatory HIV testing of pregnant women and newborns. It's likely some legislators will attempt to add similar or stronger amendments next year when the bill is considered for renewal. Many states have started to debate this issue.

It's important that those most affected by these policies communicate with their elected officials as these discussions take place. Project Inform's Treatment Action Network (TAN) will be actively involved, getting concerned people across the nation to write and call their elected representatives and express their views. If you would like to join TAN and get more information on how to get involved, contact Ryan Clary at 415-558-8669 x224 or tan@projectinform.org.

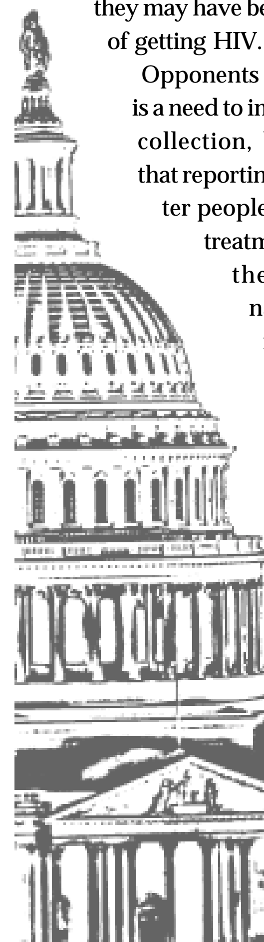
For more information on the state of HIV testing in pregnant women, call Project Inform's National HIV/AIDS Treatment Hotline and request *WISE Words #3.*

Names Reporting and Partner Notification

Currently, when people are diagnosed with an AIDS-defining condition, their names are reported to health authorities by their healthcare provider, as required by the Centers for Disease Control (CDC). Some states also require that when people are diagnosed as HIV-positive, their names must be reported to health authorities.

The CDC recently released guidelines calling for all states to collect information about HIV cases, but they don't require the use of *names reporting.* In response to the guidelines, many states recently enacted new HIV reporting laws. Some states require that all cases be reported by name, while others have implemented a ***unique identifier*** or coded system.

Supporters of a names-based HIV reporting system argue that this is the best way to collect data on the epidemic. They believe names reporting is necessary to conduct effective partner notification, in which the sexual or needle-sharing partners of someone who tested HIV-positive are contacted and informed that they may have been placed at risk of getting HIV.



Opponents agree that there is a need to improve HIV data collection, but they argue that reporting names will deter people from testing or treatment. In addition, they noted that names reporting isn't needed to conduct effective partner notification.

HIV Policy Discussions, continued

It's possible that HIV reporting will be discussed by Congress next year. Also, states without a reporting system will likely begin determining which approach they will implement. Like HIV testing of pregnant women, this issue needs the input of those most affected. To find out more on how to get involved or who in your state might be working on this issue, contact Ryan Clary at 415-558-8669, x224 or also at *tan@projectinform.org*.

Confidentiality and Medical Privacy

One especially interesting workshop focused on issues related to privacy and confidentiality. The federal government is currently developing guidelines and regulations related to confidentiality and protecting the privacy of medical records. The CDC will soon publish guidelines recommending that each state implement a *model state privacy law*. These guidelines will likely be stronger than most states' existing laws, and state advocates should work to ensure that the new guidelines are adopted. However, some states such as Minnesota already have strong laws, so it's important that advocates keep these laws in place.

In addition to the CDC guidelines, the President is currently working on creating regulations around the privacy of medical records. Congress was supposed to pass legislation on this issue but failed to meet its August 1999 deadline. It's likely Congress will continue to work on medical privacy laws, so you should let your representatives know that you want the strongest privacy protection possible.

Commentary

Many women appeared most interested in discussing local issues, such as advocating for more funding for women's services from local planning councils. Several indicated reluctance to participate in forming strategies that create a federal agenda on issues important to women with HIV/AIDS. They felt they had already provided input to federal agencies, legislators and advocates, without adequate results.

While skepticism is understandable, it's particularly crucial for women living with HIV/AIDS to participate in advocacy efforts in the coming year. Most presenters focused on the debates that will take place during reauthorization of the Ryan White CARE Act (the Act that funds many HIV/AIDS programs around the country) and in state legislatures next year. Many of these discussions will center on testing, reporting and confidentiality issues that could affect the health and civil rights of women.

These discussions serve as a wake-up call for women to develop new strategies and participate fully in the policy and advocacy process. It's simply not enough to mobilize women at the last minute when legislation is being considered. In addition, the lack of participation by many public policy advocates at this conference indicates the challenge of ensuring that women's issues get their rightful place at the forefront of federal and state advocacy.

For help in learning how to write a letter to your elected Representatives, call Project Inform's National HIV/AIDS Treatment Hotline at 1-800-822-7422 and ask for the *Grassroots Advocacy 101* Discussion Paper.

The Basic Message

- **Get tested**, *anonymously*.
- **Learn your options** and line up your support.
- If positive: **maximize your health**, **get a complete physical, a full immune health workup** and **get *informed*!** (See Project Inform's ***Day One Discussion Paper***).
- **Get baseline CD4+ and HIV RNA tests, repeat quarterly**. Chart the trends.
- **Women should get "GYN" exams and Pap tests every six months**, more often if abnormal.
- If the CD4+ trend is downward or already below 500, and HIV RNA above 5,000, **or** if HIV RNA is above 30,000-50,000, regardless of other factors, **optimize nutrition and consider combination antiviral treatment**.
- If viral measures do not decline below the limit of detection or at least below 5000, **consider a more aggressive antiviral regimen.**
- If the CD4+ trend stays below 300, **consider preventive treatment against PCP** (oral drugs if possible). If the count continues to fall below 200, **reconsider an antiviral regimen** if not already on one and **learn about preventive treatments** against other opportunistic infections. **Learn about drug interactions.**
- If you have begun preventive therapies and your CD4+ count rises as a result of antiviral therapy, **remain on any preventive treatments you have started.**
- If CD4+ count stays below 75, **intensify monitoring,** consider prevention against MAC/MAI and CMV infections. **Learn about preventive therapies.**

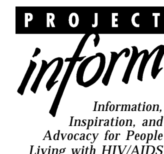
New Women's Information

now available!

Mother-to-Child HIV Transmission Discussion Paper

Also, don't forget WISE Words,

the three-times yearly publication of **Project WISE**, Project Inform's program focused on HIV/AIDS treatment information and advocacy for women. Each issue provides women with important tools for making HIV treatment decisions. If you would like to be added to the mailing list for ***WISE Words***, please call Project Inform's toll-free National HIV/AIDS Treatment Hotline at 800-822-7422, or email **WISE@projectinform.org.**



Information, Inspiration, and Advocacy for People Living with HIV/AIDS

Project Inform, established in 1985, is a national, nonprofit, community based HIV/AIDS treatment information and advocacy organization, serving HIV-infected individuals, their caregivers and their healthcare and service providers. We serve our constituents through the toll-free National HIV/AIDS Treatment Hotline, *PI Perspective*, *WISE Words* and other informational treatment publications, educational Town Meetings, online services, and research and drug access advocacy programs. All information is available free of charge. All programs depend on individual, foundation and corporate grants. Your support is strongly encouraged.

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