

wise words

A call to action: Your voice is needed

When President Bush took office almost three years ago, there was considerable anxiety about what would happen to people with HIV under his administration. His record on AIDS issues as governor of Texas was not impressive, and he said very little about HIV during his campaign.

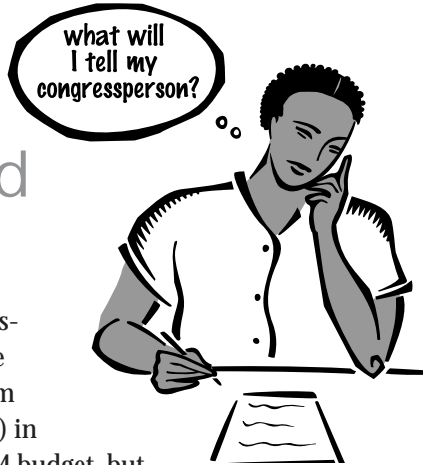
People living with HIV have been disappointed by past administrations. Even President Clinton failed in many ways in the fight against AIDS. His funding requests for AIDS programs were inadequate. The HIV immigration ban, which meant that HIV-positive people couldn't legally immigrate to the United States, became law under his watch. And he failed to lift the ban on federal funding for needle exchange programs—something he now regrets.

However, our challenges have multiplied and dramatically changed under the Bush Administration. The President has shown no leadership in providing adequate funding for the programs people depend on. For the first time since the federal government started funding AIDS programs, President Bush proposed flat funding—resulting in no increases for HIV care and treatment programs in his first two budgets. He then tried to show some commitment by proposing \$100 million increase

for the AIDS Drug Assistance Program (ADAP) in the 2004 budget, but failed to insist that Congress allocate the funding. Even the President's highly publicized promises on the global pandemic have proven to be little more than empty words.

And our challenges run deeper than broken promises to people with AIDS. The Bush Administration enacted tax cuts at the same time they are leading the country into war. Tax cuts coupled with the billions requested for the "war on terrorism" mean less money at the federal level. This has crippled our ability to fund the healthcare programs, like Medicaid and Medicare. These programs serve some of the most vulnerable Americans. This administration appears to be leading the U.S. government out of the business of providing healthcare, particularly for poor and low-income people at a time when the country already counts 43 million people as uninsured.

President Bush's philosophy on the role of government is dangerous to people living with HIV. He is willing to break promises made to people living with HIV and vulnerable Americans by underfunding the Ryan White CARE Act and threatening healthcare programs, such as Medicaid and Medicare. And for women living with HIV, who rely heavily on the Medicaid program,



Greetings Wise Women !!

Welcome to the final Wise Words for 2003!

With the changing political climate, it is ever more critical to let our voices be heard. Getting quality care that is right for you involves expressing your concerns, asking questions and communicating effectively with your doctor. Often times speaking up can be overwhelming and confusing. This issue of Wise Words will talk about ways to advocate for yourself, and your community, whether it is with your doctor or your elected officials.

In addition, there's information about the new anti-HIV drugs that were approved this year. Finally, we'll tell you about some of the work we have been doing in the community.

Have a safe and peaceful holiday season! Peace and Blessings

Shalini Eddens
Program Manager, Project Wise

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A call to action, continued

this could create real hardship and suffering. Kaiser Family Foundation reports that 61% of positive women use Medicaid compared to 31% of positive men.

Unfortunately, the new challenges posed by the Bush Administration come at a time when the AIDS policy advocacy movement is facing its own troubles. Funding for policy staff at AIDS organizations has started to dry up, resulting in far fewer people available to advocate with Congress and the Administration. There are also few staff left to run grassroots networks necessary to get information to people most affected by HIV so that they can communicate with their elected representatives. Individual activists not associated with an organization find it challenging to get support for their work.

However, this has started to change for the better. Recognizing that being effective

requires working well together, policy advocates began forming coalitions around specific challenges. Local and statewide coalitions are now forming, such as the North Carolina AIDS Action Network, along with other individuals forming their own groups.

While all of these are positive changes, we will only be as successful as the collective efforts of everyone who gets involved. That's where you come in. Our battles right now are so important that **everyone** must be a part of the solution. Our elected officials pay attention to what they hear from their constituents. The best chance we have of securing adequate funding for AIDS programs is to make sure that elected officials hear our demands directly from us.

Women are experienced advocates for our children, family members and other loved ones. However, time constraints,

health issues, work, children or other dependents can all make it difficult to become involved with these elected officials. However, it is also true that often women's voices are not heard in the policy debate and as a result needs are not met. One of the most effective ways to make change is to become involved as a citizen advocate.

The political environment has shifted dramatically in recent years. The programs that support people living with HIV and those at risk of infection are suffering. Elected officials do listen to voting constituents. Your help and action are essential to making a difference. Whether it's writing to your elected representatives for the first time, challenging candidates about their vision for fighting AIDS, or joining a group and organizing your own community, you can be part of the solution. After all, if not us ... then who?

These are some ways that might help you take action.

Educate yourself

Take some time to learn more about policy issues and what role you can play as an advocate. While you don't have to be an expert on the issues or the legislative process to be effective, it does help to understand the basics. For example, it is helpful to know what decisions are made at the federal, state, and local levels so that you can target your advocacy with the right elected officials. Pick one or two issues so that you don't get overwhelmed.

You can find many good resources on Project Inform's public policy resource guide at www.projectinform.org/org/presources.html. You will find national, state, and local organizations that engage in AIDS advocacy on a variety of issues.

Join an advocacy group or coalition

You might consider being part of a local, state, or national advocacy group. Many of us prefer to do advocacy with others, whether it is a neighborhood group, your support group or a large national group. Even if you don't have experience with this type of advocacy, you bring expertise based on your

own life experience. Most groups are happy to provide training or mentorship in advocacy work. You might contact a local organization listed on Project Inform's resource guide and ask what groups or coalitions you can join.

Your vote does make a difference

One of the most important ways you can get involved in AIDS advocacy is by getting involved in the 2004 election. If we elect the right leaders, fighting for adequate funding and protecting important programs would be much easier. In November of 2004, not only will we decide who becomes President, but all House Representatives and one-third of the Senate are up for re-election. This provides an excellent opportunity to elect new representatives and to educate candidates as they campaign.

One way you can get involved is by joining Project Inform's Treatment Action Network. To join TAN, go to <http://projinf.fauldhouse.com/tanlist/tanlist.php4>, or send an email to tan@projectinform.org with "subscribe" in the subject field.

The ultimate goal of AIDS treatment and research advocacy is to accelerate the pace of scientific discovery toward a cure for AIDS. As we progress toward this goal, including new HIV therapies, new issues emerge, such as the need for research to better understand and manage drug interactions and side effects of new medications. People living with HIV and their advocates have dialogued with scientists since the early days of the epidemic, conveying community needs for research and working to influence what is researched and how research is conducted to better serve the needs of all people living with HIV.

Fundamentally, what is researched and how things are researched results in what we learn about HIV and its therapies. For example, if women are not included in a research project and/or if questions about how a drug or HIV is impacting women are not asked from the beginning of a research project, then when it's finished women-specific information can't be expected from it. This doesn't mean that the study results have no meaning or relevance to women, but the information would have limitations.

Treatment and research activism is not always easy to do. It takes time and determination and can feel intimidating and overwhelming at first. Many of us don't have science

backgrounds or special educations that help us understand the world of research and science. Science is a very male dominated field and women, including women working in sci-

There are many ways to influence research. But how do you start?

ASK YOURSELF QUESTIONS ... like the ones above. What questions do you have about HIV and therapies? What's important to you? The goal is to understand what barriers exist for you, and people like you, to participate in research and what can be done to address and remove those barriers; to change both the type of research as well as how research is conducted. You have answers to these questions and your perspective and ideas are much more valuable than perhaps you realize!

LEARN. Sometimes our most pressing questions have already been addressed by research, and answers exist. Other times, perhaps more often, the questions we have are exactly what researchers need to hear to inspire new research. As you start to answer your own questions, it becomes apparent what has and hasn't been done—where there is and isn't information from studies.

TAKE ACTION. There are several places you can take the issues that are important to you. One place is directly to HIV researchers in your area. Set up a meeting and talk with them about your concerns. Many academic institutions have public hospitals with large research programs. You may have an AIDS Clinical Trials Unit (ACTU) or a Community Program for Clinical Research on AIDS (CPCRA) site in your area. These groups have local community advisory boards (CABs) that meet regularly to get input into research and hear and respond to concern.

They also have national community constituency groups (CCGs), providing community input into their national research agenda. These groups are always looking for people interested in bringing a new perspective to AIDS research, inspire new ideas and assure that research addresses the concerns of all people. There are also CABs for the Women's Interagency HIV Study (WIHS) and other networks that focus on or include women like the Women and Infants Transmission Study (WITS). Becoming involved with these groups is a great way to start, and other community members who are involved can help and mentor you.

Recently, a network of activists around the country have begun building a coalition—the AIDS Treatment Activist Coalition (ATAC), who support and mentor one another while working together on treatment activist issues. Their website, www.atac-usa.org, is a great place to go to ask questions, learn about treatment activism, meet others just beginning to get involved and find mentors.



ence, often times find it hard to be heard by the powers that be.

Each of us brings unique life experiences and perspectives to the table. What questions are important to you and your loved ones relative to HIV? What questions do you have about treatments and how they are (or are not) working in your body? What barriers do you have (and other's like you) to being in a study? What would remove those barriers? What kinds of HIV research would you participate in and why? What do you think AIDS research priorities should be and why?

When you ask yourself these questions, what are your answers? Who will represent your concerns to the research establishment so that they get addressed? If not you, then who? Making your voice heard will effect changes that will benefit you, our children and future generations—to realize a cure and a world without AIDS.

In the late 1980s and early 1990s, when women asked themselves these questions, one of the answers was, "I would participate in research, but most of the studies won't allow women of childbearing potential to participate." An entire range of women from girls who just began menstruating up to menopausal women were excluded from most studies of new therapies. Industry and government didn't want to bear the burden of legal concerns if a woman in a study became pregnant and a new drug impacted the healthy development of her unborn baby. Treatment activists got together to change the system. Now, unless there is some strong scientific reason, women cannot be excluded from research merely because they could have a baby. Instead, most studies now either require the use of birth control and/or make provisions for women who do become pregnant. Several studies of anti-HIV drugs have only included women, and there are research networks that focus almost exclusively on women and HIV.

It will take a bit of heroism from each of us to realize our visions of our communities, our futures and our lives. Your voice, your vision of the future and your celebration of life are needed in the fight for better research towards a cure.

Lorraine Brown is Client Advocate for McDowell Health Center in Phoenix, AZ. She has been positive for 18 years. Lorraine contacted Project Inform to share her personal story. As she spoke up for herself, doors were opened for her and her family. Lorraine now works as a client advocate encouraging other positive women to speak up for themselves and those they love and care about. Her story is one of strength, determination, persistence and ambition. Read on for words of wisdom!

How did you become a client advocate?

I was a volunteer at the clinic I currently work at and my supervisor said that they had a position open for a client advocate. Before that, I was trying to get disability and I got denied three times before I got it. I had to stay with my folks because I could not afford my rent. The disability office said that because I stayed with my folks I didn't need disability. I kept calling and going to their office with papers from my doctor stating that I was disabled. I told them that by denying me disability, they were causing my children to be homeless, without clothes and hungry. They eventually knew who I was and recognized my voice when I called and realized that I was

not going to stop calling or coming in until they gave me disability. I made sure that I provided for my children.

You need to be persistent and stick to it. Let them hear your voice and see your face. You have to stick to your agenda and don't beat around the bush. Always state the bottom line, this is what I can and cannot do without this program ... I have no roof, I have no clothes for my children or myself, I have no food.

telling my family about my hiv was important to me



What has made advocating for yourself easier?

The support of my family. The best way to find out if someone cares for you is to disclose to them [that you're HIV-positive]. If they really care about you they will stand by you. Having someone there to support you makes your fight easier; they can fight for you when you're not able. When I was very sick with severe thrush and unable to get out of bed, I ran out of food stamps. My parents went and spoke for me, with a note from the doctor explaining my situation and how important it was for me to have those food stamps.

By telling my family [about my HIV] they have gotten to know me better. They realize how it can affect them and that they may be doing things that are high risk [for HIV infection]. My brother and sister were engaging in high risk behavior and

didn't even realize it or think about it until I disclosed. I found out that I had two cousins who were gay and positive and they had not disclosed.

When you disclose to family and friends, remember these four important things:

- Know the reason why **you** want to tell them.
- Have someone with you who is supportive, so they can support you if you're rejected.
- Prepare yourself for rejection.
- Remember that even with rejection, something good can come. You have left someone with education, with information that they may have otherwise not had.

What were some of the challenges you experience in advocating for yourself?

When I was first diagnosed, the first thought that came to my mind was what was my family going to think of me? I was not accepting what was happening to me. I didn't know I was at risk, so my diagnosis was a surprise to me. The providers didn't know what to do with me because I am an African American straight woman, not a gay man!

When I met another positive woman undergoing some of the same things I was going through, I realized that I was not alone. She helped me find the support and resources that I needed.

I told my sister six months after my diagnosis. We cried and laughed together. I brought her along with me as I told other family members.

How have you advocated for yourself with your doctor?

When I moved to Arizona I heard about an HIV specialist that was supposed to be really good. I brought copies of my medical files from my other provider and went to see him. I started menopause early and had been on hormone replacement therapy. My new provider in Arizona told me I was too young to be starting menopause and the symptoms that I had were probably a result of my regimen, which were Kaletra and Sustiva at the time. He changed my meds to Trizivir and Viramune. I started to experience neuropathy and sharp pains in my breasts to the point that I was unable to get up, and the pain was so bad I couldn't be active and take care of my kids. My doctor prescribed me Neurontin. Every time I went to the doctor and would tell him that I was not able to handle the neuropathy, he just kept increasing the Neurontin.

I finally told him that he was not listening to me. I wanted a working relationship with my doctor and unless he was looking to work with me, I will need to take my care elsewhere. I told him, "I am firing you." He told me that he had never been fired, and then refused to forward my files to my new provider. I had

copies of all my medical files and took them to my new doctor.

I called my case manager and asked for a list of both HIV specialists and primary care providers who had an interest in HIV. I called everyone on that list and made a stack of docs who took my insurance.

On my first day with the new doctor, I brought a list of questions. I asked her opinion on her patients wanting to try alternative therapy. She said as long as I tell her everything that I am doing and bring in a list to her, she was fine with that. I asked her, "If I tell you that I have an issue with something will you address the cause?" I explained to her my previous issues with my doctor and then we talked about my records. After she answered all my questions, I told her, "You're hired." She put me back on my old regimen and told me that she would run some tests to validate everything from the records. When I left she told me, "Just let me know what you're doing with your health, whatever it is."

I also found a naturopathic doctor (NP) who has helped me to find other ways to deal with my neuropathy. My NP and my primary doctor talk. I want them to work in sync. One day I had my NP call my primary care doctor while I was there, and my primary care physician always faxes my lab work to my NP. I told them both, "I hired you guys to give me the best quality care, and I want you both to work together on this." It's important to remember that you have to make it happen, whatever it is. Now the two of them do workshops together!

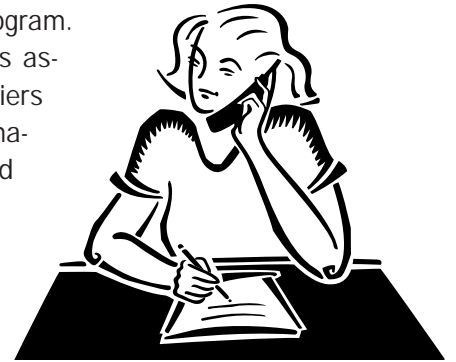
What kinds of questions do you think someone should take to their provider when they're interviewing them?

It's important to be prepared. It's important to make sure you're going to get the care that you need. It is different for different people. Know what your cause is. What is it that you want to get? What is important to you? For example, the Neurontin made me drowsy, and I didn't like that. It was important that I find another way to deal with the pain and that I had a doctor who would work with me. So it was important that they be receptive to alternatives to dealing with neuropathy. What do you expect from your doctor? It's about you and what you want. The key thing is that you know your own issues and concerns. Advocating for yourself means homework; you have to find out what is out there.

Any final words you would like to share?

With HIV or any other disease where you can be here today and gone tomorrow, it's important to look around you. Enjoy what's around you. Be grateful you have the chance to experience these things. I use affirmations to help me realize my self-worth. I allow good things to happen in my life. Feel worthy. Think to yourself, "I am worthy of this." Enjoy what you have that is good and believe that you are worthy of it!

Community input is key to a successful and sustainable program. For this reason, Project Inform conducted a women's needs assessment this year. Its goal was to identify gaps, needs or barriers HIV-positive women may have in accessing and using information about treatment and care. The needs assessment helped Project Inform to understand how to better serve the educational, public policy and treatment/research advocacy needs and concerns for women living with HIV/AIDS. This article talks about the results of the assessment and how they will impact the women's program at Project Inform.



METHODS

Interviews were conducted with women living with HIV, including women who use Project Inform's services such as the hotline, key staff from community-based agencies serving positive women around the country, women living with HIV and Project Inform staff and volunteers. The survey included questions about where women get treatment information, challenges women may face in getting or understanding treatment information and medical issues that women living with HIV experience. Twenty-five interviews were completed and included women from New Jersey, DC, Georgia, California, Texas, Connecticut, Mississippi, Louisiana, South Carolina, and Maryland.

RESULTS

HIV treatment information

Survey participants reported that most women receive HIV treatment information from newsletters, doctors, nurses, case managers, the Internet, AIDS service organizations and/or peers. Most expressed that they learn from both written (like fact sheets) and verbal (workshops) information. Participants reported, however, that some women living with HIV experience challenges to using HIV-related information. Some of them include a lack of information in languages other than English, a lack of information that is less technical or medically advanced and difficulties of getting and using information when a woman is incarcerated.

Healthcare

Medicaid, Medicare, AIDS Drug Assistance Programs (ADAPs) and private health insurance were

reported as being the primary sources of payment for women's HIV care and treatment. Community clinics, infectious disease clinics in hospitals, emergency rooms and private doctor's offices were the locations that most women appear to be getting healthcare. As with treatment information, the survey participants also identified barriers that stand in the way of some women receiving optimal care. These included transportation problems, language barriers, doctors/nurses not explaining care plans sufficiently, and discomfort or embarrassment over not knowing how to ask questions.

Living with HIV

People reported a wide ranging list of issues that they felt had a major impact on the well-being of women living with HIV. These included inadequate housing; low income; taking care of a family while managing one's own health; stigma, difficulties and risks of disclosure; hepatitis C and gynecological concerns. Concerns about HIV treatment were primarily about side effects, body image changes, and long-term safety of therapy.

What can Project Inform do to better serve women?

Overall, most people interviewed suggested that Project Inform's women's program was a useful and needed resource for women living with HIV in the United States. In general people felt that it should focus efforts in the areas of community education and advocacy for women living with HIV. For example, one participant felt that the program could develop education workshops on treatment and concerns for women living with HIV. Finally, the newsletter *Wise Words* was seen as a valuable and resourceful publication!

What does this mean for Project Inform?

The needs assessment affirmed the efforts Project Inform has made to serve women living with HIV. These include:

- Project Inform's national hotline that provides treatment and care information and support;
- Project Access, which provides healthcare access support;
- regional town meetings for people living with HIV and provider trainings;
- publications, including *Wise Words* and *PI Perspective*; and,
- policy activities that have a particular focus on federal healthcare programs such as Medicaid, Medicare and ADAP, all of which women reported using in the needs assessment.

The outcome of the needs assessment also sheds light on new directions that Project Inform will take to improve services to women living with HIV. Of note, the importance of education and advocacy for women with HIV was repeatedly identified as areas of increased need and attention. More education programs that are for, by and about women were a clearly identified unmet need. In addition, many spoke of the need to build a national advocacy voice for women and support women to be advocates for themselves, their families and their community. In 2004, Project Inform will work to further strengthen these efforts.

It's Project Inform's hope that this process will not only continue to build a solid foundation for the women's program at Project Inform but also help to create a voice for women living with HIV/AIDS. In addition, continued input and feedback is critically important. The needs assessment is a continuing and ongoing process, so if you would like to participate please call and lend your insights and ideas! You can contact Shalini Eddens at 415-558-8669 x205 or email at seddens@projectinform.org.

Keep your eyes and ears open for more news and updates as the process continues.

In 2003 four new anti-HIV drugs have been FDA approved, including the first drug in a new class called *entry inhibitors*. To varying degrees, each of these drugs offers something new and important to the toolbox of approved anti-HIV drugs. What follows is a brief overview of each drug, with its plusses and minuses and what we know about their use in women.

Enfuvirtide

The first of the newly approved drugs was enfuvirtide (Fuzeon, T-20). Enfuvirtide is a new kind of drug from the *entry inhibitor* class. It is the first anti-HIV medicine that attempts to keep HIV from getting inside cells. All of the others attempt to stop HIV that has already entered a cell from reproducing.

The key benefits of enfuvirtide are related to the unique way it works. Because it works outside of cells, it doesn't have many of the same side effects as other anti-HIV drugs. Also, it works well in people who have resistance to other anti-HIV drugs.

However, there are three drawbacks to enfuvirtide. First, it requires two injections a day. This can be inconvenient and possibly intolerable for people who are not comfortable with needles. Next, most people experience some degree of pain, swelling and redness in and around the area of the body where they inject it (called injection site reactions). This problem might be lessened somewhat if there's some-

one around—a partner or roommate—who can give some of the shots, allowing people to inject in more parts of their body. The third problem is the cost. It is by far the most expensive medicine approved to treat HIV. This may keep some people from being able to get the drug paid for.

Enfuvirtide is approved only for use in people with multiple drug resistance. Because it must be injected, it will probably never be used as first line therapy.

Although enfuvirtide wasn't studied in many women (around 10% of the people in studies were women), scientists observed that it stays in women's bodies longer than men's. It is unknown whether this has any impact on side



new drugs on the horizon, continued

effects or its effectiveness. In animal studies enfuvirtide did not cause birth defects or other problems with pregnancy. No studies in pregnant women have been done. For a fuller discussion of enfuvirtide, call Project Inform's hotline or visit www.projectinform.org.

Atazanavir

The next drug to be approved this year is the new protease inhibitor (PI), atazanavir (Reyataz). Atazanavir offers two advantages over other PIs. First, it is the only one approved for once-a-day use. This can provide a benefit for people seeking a simplified dosing regimen. The second advantage is that atazanavir hasn't been shown to increase cholesterol and triglycerides (types of fats), which is a problem to various degrees with all the other PIs.

The drawbacks of atazanavir revolve around potency, side effects, drug interactions and cross-resistance. Although the studies have been somewhat unclear on atazanavir's strength, it appears to be stronger than nelfinavir (Viracept) and weaker than Kaletra (lopinavir/ritonavir). In other words it seems like an average strength PI. Although it doesn't have the blood fat problems seen with other PIs, around a third of people experience a rise in bilirubin levels, which may cause a yellowing of the skin and eyes (*jaundice*). While increased bilirubin is usually a sign of liver problems, this is not the case with atazanavir.

Atazanavir has a long list of drug interactions. People taking atazanavir should work closely with their doctors and/or pharmacists to identify any possible drug interactions and make any necessary dose adjustments.

We do not currently know the level of cross-resistance that atazanavir has with other PIs. More research is needed before we can be sure how well atazanavir will work in people whose virus has become resistant to other PIs.

Atazanavir can be used in two ways. For people just starting therapy or who have never taken PIs, atazanavir can be taken once a day with food in combination with other anti-HIV drugs. People who have developed resistance to other PIs will need to take atazanavir with a small dose of ritonavir (Norvir), which increases its effectiveness. One drawback to this is that ritonavir, even at this low dose, can increase cholesterol and triglycerides. However, this increase is still less than what's seen when ritonavir is taken with other PIs, including Kaletra.

Thirty-five percent of the people in studies of atazanavir were women. No differences were observed between men and women. In animal studies atazanavir did not cause birth defects or other problems with pregnancy. No studies of pregnant women and atazanavir have been done. For a more thorough discussion of atazanavir, call Project Inform's hotline.



FTC

The third medicine to receive FDA approval was emtricitabine (FTC, Emtriva). A close cousin of the older drug lamivudine (3TC, Epivir), emtricitabine perhaps has the least new to offer, at least for now. Because it is so similar to lamivudine, emtricitabine will usually not work for people who have developed resistance to it. It has similar side effects as lamivudine, including headaches, nausea and diarrhea. Emtricitabine is taken once a day. There may be more interest in emtricitabine in early 2005, when its maker Gilead plans to combine it into a single pill with tenofovir (Viread), as an obvious competitor for Combivir.

About 15% of the people in emtricitabine studies were women, and no significant differences were seen between men and women. In animal studies emtricitabine did not cause birth defects or other problems with pregnancy. No studies of emtricitabine have been done with pregnant women. For a more thorough discussion of emtricitabine, call Project Inform.

Fosamprenavir

The fourth drug approved this year is fosamprenavir (Lexiva). It is a new form of the older protease inhibitor, amprenavir (Agenerase). Its main advantage is fewer pills (2 pills a day vs. 16) than the older form, which may improve adherence. The most common side effects are diarrhea, nausea and rash.

No significant differences were seen between men and women in studies of fosamprenavir. Although studies of fosamprenavir and pregnancy have not been concluded, we can look at the data from amprenavir studies. In animal studies amprenavir did not cause birth defects. For a more thorough discussion of fosamprenavir, call Project Inform.

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