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wise words

hiv/aids treatment information & advocacy by and for women

VOTING: your right and responsibility

"This could be the defining election of our lives." "Voting is your right and responsibility." "Vote as if your life depended on it."

You've probably heard all these slogans. Most likely you've seen the political ads and maybe even watched the conventions. So, what's the urgency about; why does voting matter? It's easy to get cynical about voting, especially in national elections where many have been faced with barriers to voting, had their votes discounted or simply haven't found a candidate who speaks to them or their issues.

However, the President, the Administration and those who represent us in Congress can have a huge impact on our lives and those we care for. As women and people affected by HIV, our concerns, at best, have gone unaddressed in the last four years. At worst, the programs we care about and depend on have been attacked and insufficiently funded while unhelpful, even destructive, policies have been put in place. Tax cuts benefiting primarily wealthy individuals, war spending, and slow economic growth have left little for important domestic programs such as education, healthcare and social services. In HIV/AIDS, we have seen essentially flat funding for the Ryan White CARE Act for the first time since its inception. Medicaid has been the target of proposed cuts and reductions in service.

The Medicare Prescription Drug benefit that was to help seniors and disabled people with overwhelming drug costs will provide some relief but may also leave some worse off than they were before the benefit.

Voting is one of the most important ways you can make clear what matters to you and your loved ones. However you choose to vote, know the candidates' platforms on the issues you care about, including HIV/AIDS. One place to check is AIDSVote (*www.aidsvote.org*). This site defines what the next President must do to address the AIDS pandemic. You can view the platform, endorse it, read the candidates' responses, view candidates' profiles, get involved with an absentee ballot drive, download materials explaining the role of nonprofits in electoral politics, and learn about the "Rally in a Can."

Many of you who read this article already plan to vote. You may have made a decision on your candidate. And you may feel this article is preaching to the choir. If this is true for you, you can still make a difference by helping others exercise their right to vote.

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WHAT'S WISE INSIDE

Greetings Wise Women!!

Welcome to the 15th issue of *Wise Words*. Women are living longer with HIV these days and doing things they probably never thought they could do. Having children, working, traveling, going back to school, and getting involved in the community are just a few of the steps that positive women are taking in their lives. Managing your HIV or making decisions about your next regimen may not be the first thing on your mind.

This issue includes articles about resistance, third line therapy, and stories from women who have been positive for many years. The public policy section talks about the importance of the upcoming election and voting. Finally, we would like to continue to make *Wise Words* relevant to the lives of positive women, so your input is key. A reader survey is included on page 8. Please take 15 minutes of your day to complete the survey and mail it back to us. We will include the results in the next *Wise Words*.

All the best in your decisions ... Peace and blessings.

Shalini Eddens

Shalini Eddens
Women's Program Manager

Wise Words is a program of PROJECT inform

Start by knowing who votes. According to the US Census Bureau, in the last national election, 111 million people or 55% of the voting-age population voted. The average voter is older, white (non-Hispanic), and female. 72% of voters were between the ages of 65–74. Only 36% of 18- to 24-year-olds voted. One young woman explained, "I don't feel that most politicians today understand or care about the issues that are important to me or people my age, so why should I bother to vote at all?"

In 2000, 62% of White non-Hispanic citizens voted, the highest level of turnout, followed by 57% of African Americans, 45% of Latinos, and 43% of Asian and Pacific Islanders. Women were more likely to vote than men (61% compared to 58%).

Why aren't people voting? A US Census Bureau report identifies some of the reasons:

1. Too busy or conflicting work/school schedules (21%)
2. Illness, disability, or family emergency (15%)
3. Not interested or felt their vote wouldn't matter (12%)
4. Out of town (10%)
5. Dislike candidate or campaign issues (8%)
6. Confusion or uncertainty about registration (7%)
7. Forgetting (4%)
8. Transportation problems (2%)

For 501(c)3 non-profits interested in engaging in political activity here are some things to consider:

1. Can engage in limited lobbying, including work on ballot measures.
2. Can conduct nonpartisan public education about participation in the political process.
3. Can educate candidates on issues.
4. Can conduct nonpartisan get-out-the-vote and voter registration drives.
5. Cannot endorse candidates for public office.

For complete information on permissible election activities for 501(c)3 nonprofits visit *www.allianceforjustice.org*.

Now that you know who votes and some of the reasons why others don't ... you may ask yourself, "What can I do?" Here are some ideas:

- **Start your own "get out the vote" project.** Are there people in your community who might be less likely to vote? With a small group, brainstorm ways you can help people in your community be more involved. Decide on the best ideas. Take action.
- **Educate yourself and others.** Check out political websites, such as *www.AIDSVote.org*, League of Women Voters (*www.lwv.org*) or *www.rockthevote.com*.
- **Apply peer pressure.** You remember peer pressure from high school. Well, now you can use it to do something positive. Call friends and family; encourage them to register and vote.
- **Get connected, stay engaged.** Once the political machines start rolling and the media floodgates open, we can get mired in the mud of electoral politics. It's easy to get frustrated and disillusioned so stay connected with a group or groups you trust.
- **Give money.** Find an organization that best represents you; give what you can.
- **Plan a registration drive.** The League of Women Voters' website has "Ten Steps for a Successful Registration Drive."
- If you know people who may have trouble getting to the polls on election day, **help them get an absentee ballot**. Visit *www.aidsvote.org* for information.
- **Become a poll worker.** Contact your local election office or the League of Women Voters.
- If you're a student, **arrange a polling place on campus**. Visit *www.rockthevote.com* for more information.
- **Volunteer** to assist those with disabilities or transportation issues get to the polls.

Voting is our right as well as our obligation. We can't take it lightly or ignore it. As women and as Americans, it's even more important for us to vote. Many women in other countries continue to fight and even die for this essential right. We can make a difference as long as we participate and speak up.

what is resistance?

HIV can grow resistant to the drugs that are used to treat it. This means that the virus changes in ways that can make the drugs less effective, or even totally ineffective. This can happen because people are not taking their drugs regularly as prescribed or a drug combination is not strong enough to keep the viral load down or low. There are two big concerns when people develop drug resistance: treatment failure and loss of future treatment options.

When one or more drugs in a regimen stop working, HIV reproduces in greater quantities. If a person doesn't switch to a new regimen, this can damage the immune system and accelerated disease progression. An increase in viral load is often the first sign of drug resistance. So, it is important to have a viral load test regularly—at least every three months.

Developing resistance to one drug may sometimes mean that other drugs will not work as well. This is called cross resistance. For example, consider the non-nucleoside reverse transcriptase inhibitors (NNRTIs) that include efavirenz (Sustiva), delavirdine (Rescriptor) and nevirapine (Viramune). All of these drugs can stop working if the same mutation (change in the virus) occurs. If you develop resistance to one of these drugs, the other NNRTIs may not work well.

HIV can become resistant to all of the currently available anti-HIV drugs. However, some drugs are more powerful than others, and it may take longer to develop resistance. The two keys to preventing resistance are 1) using a potent regimen and 2) taking all the pills in the regimen on time and as prescribed (adherence).

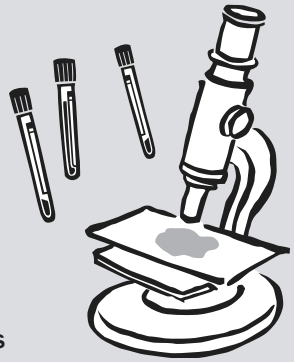
... continued on page 6

What do I do if I am resistant to everything?

What do you do if your virus has developed resistance to all the available drugs? Should you keep taking a regimen while waiting for new drugs to become available even if your virus is resistant to all of the drugs you're taking?

There is evidence that it is better to stay on therapy than to go off altogether. A number of studies have shown that staying on a failing regimen often still provides some degree of viral suppression and is thus less harmful than going off of medication altogether. These studies assume, though, that a person is not having serious side effects from the drugs. The risks of going off of anti-HIV drugs are significant, particularly if your CD4+ count has ever been below 200 or if you have had an AIDS-defining opportunistic infection.

Why might someone benefit from staying on drugs that their virus are resistant to? There are three things that might help explain these observations. The first is that resistance is not an all or nothing thing. HIV can be partially resistant to a drug—that is the drug works to a degree, just not as much as if there were no drug resistance. Stopping some amount of viral reproduction is probably better than none at all.



Second, people living with HIV generally harbor different populations of virus in their body. Commercial resistance tests only test the most numerous, or dominant population. So, a smaller population of virus that might still be sensitive to one or more drugs will go undetected. So a drug regimen might retain some anti-HIV activity even when resistance tests show total resistance.

Finally, the changes which a virus goes through to become resistant to a particular drug can sometimes make that virus less "fit." For more information on this topic, see the box on page 6.

It takes a tremendous amount of courage and faith to face our fears, but each one of us has the power to create happiness in our lives. The words and experiences of positive women can be inspiring and motivating. We talked to some positive women who have been living with HIV for awhile. We got their expert advice on living with HIV, disclosure, adherence, working with their doctors and how they got through some of their darkest moments. Each one has dealt with her diagnosis differently and had successes and challenges. However, the one common thread is the amazing inner strength that these women possess.

cathy

Cathy is very active in the community and has been living with HIV for over five years. She encourages women to take a stand and have a healthy attitude.

On disclosure ...

It's also harder for people who have not disclosed, because there's shame and without any support it is difficult. Everyone in my life knows that I'm positive. So I never need to hide anything from anyone. It creates a sense of normalcy. I don't feel ashamed to have to hide anything and I feel in a better position to help other women.

Knowledge is power ...

What has helped me is to be educated about the medications. I know now if something is making me sick, I immediately talk with my doctor. It's important to be able to go to your doctors and talk to them. Stand up for yourself. Be an assertive patient.

On taking medications ...

I started taking Combivir (3TC/AZT) in 1996. I was on that medication for a couple of years. There was no resistance testing at that time. Then I switched to nelfinavir (Viracept), ddI (Videx) and d4T (Zerit) and was on that for one and a half years. Got really tired of the diarrhea, I just wanted to have a bowel movement.

Then the guidelines changed and treatment breaks were introduced. I went off meds for two years. My T-cells were 760 when I stopped them and they started to drop down. When they got really low, I went onto efavirenz (Sustiva), tenofovir (Viread), and ddI EC (Videx EC). At this point I had never had a resistance test.

I believe that the healthier you are when you start, the better luck in tolerating the medications. I've been very lucky. I also think that if you have the opportunity to consider medications around 300–350, this might be a good time to think about medications. It's all about your frame of mind and how you look at it.

linda

Linda was diagnosed in 1992. Finding a way to continue living and do what she wants to is what has kept her going.

On being diagnosed and taking meds ...

My first thought was, "Okay, so I have this. So what do I do?" At the time, I didn't know anything except that I needed to be on medications, so that's what I did. I did what my doctor said, and I went along with it.

The first major side effect was diarrhea from the Viracept and nausea. Then I took amprenavir and I got a lot of nausea. I had to stay on it and deal with it and I thought this is how it's going to be forever.

I have to go by how I feel. If I'm taking something and I feel bad, it doesn't work for me. I had to find something that would work where I wouldn't feel like crap.

I took Kaletra and experienced lipodystrophy. Every time my doctor suggested changing I dreaded it. I thought, "Are they going to change my medications? What new thing is going to happen to me?" I got very sick on Crixivan too. That feeling of the unknown ... am I going to be sick again.

I was never adherent, because of the side effects. It's hard to take something that you know will make you sick.

In November 2002, I heard good things about atazanavir so I thought I would switch. It's been the best regimen I've ever been on. I take it once a day. It can become a part of your life and not take it over. I'm now adherent!

If I can't live my life the way I want to live it, then it won't work for me.

Network, support and education ...

Talking with other positive women was helpful. I asked, "Have you been on this med? What do you think? How does it work for you?" I tried to get a real understanding. I have to read everything. I have to know everything. All the newsletters, the internet, books. Especially anything specific for women.

I have learned which parts of my body are and

Positive living ...

HIV use to be very consuming in my life, but now it's not consuming. I couldn't live on that level. There has to be a balance between HIV. I still keep up—doesn't feel like I need to do this to save my life. In the beginning there was an urgency. Now I know what I need to take care of myself.

I've been able to find a balance—this can't be the only thing in my life. I started to look at the bigger picture. It was my life—rather than a moment in my life.

On disclosing ...

"I was diagnosed with my husband. I wanted to tell everyone, but my husband didn't. It was this big secret—so we didn't tell anyone for nine months. When we did tell everyone, they were very supportive. No one was very mean or rejected us.

I always thought it was better to live your life openly ... what a horrible life to live with a secret. You can feel very isolated. The more people you have in your life to support you, the better you will feel emotionally, mentally and physically. It's not a secret. It's enabled me to do what I want to do.

I did an interview on TV and it was on the early evening news. As it got closer to the time that I was going to be on, I got really nervous. I didn't call anyone to tell them I was going to be on. So when it was on, I thought—wow it's out there. ... there's nothing I can do. And it was very empowering. It was huge! All of my guts are out there! Taking a huge fear out into the open that wasn't bad.

It's really about your whole life. You can live with this disease. There's no decision that you have to make right now. You can take some time to think about it and figure it out if it is the best decision for you.

dorothy

Dorothy was diagnosed in 1989. Her motto: "Me and the HIV were in the game together."

On knowing your body ...

I have learned which parts of my body are and aren't strong. I can look at the meds and get a sense of side effects and how they will affect me. I know that any of the meds with neurological side effects I can't take. I know that my digestive system is pretty strong so I can manage the ones that might affect my digestive system.

Watch your body. Study your body on the regimens. Take mental notes. Get in touch with your body. Look for subtle tones in your body.

There is a relationship between the drugs. If one gives you diarrhea, another with the similar side effect may give you the same thing.

Tips to advocate for yourself ...

When I went to the doctor, I prioritize what I am going to ask them. It can be really hard to get a doctor to listen to you. Focus on the major symptoms or problems in the beginning of your conversation, the ones that are crucial. Write things on a piece of paper. My acupuncturist said it helped her ... I itemized all the things that were bothering me.

Adherence is crucial ...

I was so determined to live. Adherence is crucial; I was so close to death. I remember going to an AIDS conference and I had to fast cause I was taking Crixivan where you have to fast for three hours when you're taking it. My friend ate French fries and felt bad, but I told him, "No, I'm choosing to fast for Crixivan."

That was a moment of clarity. I was in charge of my own medical care; it's never been the fault of my doctor. I made that choice.

The tough times ...

The first 1–3 years were real hard, then it gets easier. Then I got really sick; it was hard to get through seven years of being in bed. I had MAC, PCP, and my energy never came back. I had massive fatigue. My kidneys flared up. I told my doctor that in six months I was going to commit suicide. I thought this is really stupid that all I was doing was watching TV. My doctor replied, "Either I could help you or if we have six months—let's get busy."

What helped me to survive? There's an African freedom song, goes something like "a long walk to freedom." Life doesn't want to die in you. Find people; go talk to someone else who may be going through a difficult time.

Self pity is a deadly thing—we must break the cycle. I had to resolve the anger. I had to find someone in worse shape than me and help them. That put things in perspective for me.

I try to put as much fun in my life as I can.

How is resistance tested for?

Several tests are available to check for drug resistance. There are two types: genotypic and phenotypic.

Certain changes in HIV's genetic material will make particular drugs less likely to work. A genotypic test looks for these kinds of changes. The genotypic test results will tell you these changes, and predict which drugs are likely to work.

Phenotypic tests take a person's virus and expose it to anti-HIV drugs in a lab, to see which ones will work to suppress HIV reproduction. The results of a phenotypic test will tell you how well each drug suppressed the virus in a test tube. Phenotypic tests can sometimes provide more detailed information about resistance.

Resistance is not an all or nothing thing—there are degrees of resistance. A drug might have reduced potency, or partial resistance, yet still some potency to be useful as part of a regimen.

With both types of test, the higher a person's viral load at the time the test is run the more accurate the test will be. Genotypic tests require a viral load of at least 1,000 and phenotypic tests a viral load of at least 500. A phenotypic test can sometimes show partial resistance more accurately than a genotypic test. However they are more costly, take longer to run and might be less likely to be covered by insurance. Genotypic tests are more commonly covered as they are faster and cost less. The results of both kinds of tests require expert interpretation.

By the time a person goes through several anti-HIV drug regimens, it is quite possible they will have developed some resistance to many drugs. This is called multi-drug resistance. Choosing a next regimen in the face of multi-drug resistant virus can be a challenge. However, expert guidance combined with genotypic and phenotypic test results can usually result in a combination that is effective. (For more on anti-HIV strategies for third line therapy, see page 7.)

It is always best to have a regimen that contains at least two drugs that HIV is not resistant to. So, if a new drug that you are not resistant to becomes available, it will work better if you combine it with older drugs. Resistance tests can help you pick the best possible drugs to use in this situation. As is always the case when constructing a drug combination, it is important to think about the possible side effects and drug interactions of the combination being considered.

Conclusions

The use of anti-HIV drugs is limited by the development of drug resistant virus. While it may not be possible to stop resistance from forming, it can be slowed down a great deal. The keys to preventing, or at least delaying the development of resistance are to be on a potent regimen and to stay adherent. If resistance is suspected, genotypic and/or phenotypic resistance tests can help guide you and your doctor in developing your next treatment regimen.

Can resistance be good?

In general, resistance to anti-HIV drugs is something to be avoided, as it can lead to reduced suppression of HIV and possible treatment failure. It also limits future treatment options. Not all drug resistance is equally bad, however. In fact, it can even be helpful in some ways.

To understand how drug resistance can be helpful, it's important to understand *viral fitness*. Viral fitness refers to how well the virus is able to reproduce. Drug resistance can affect viral fitness. When HIV makes copies of itself that are able to reproduce in the presence of anti-HIV drugs (i.e. drug resistant virus), those copies of the virus sometimes can't reproduce as well as the original version (known as "wild type" virus). When HIV changes enough to become resistant to certain drugs, it does so at a significant cost to itself.

Some of these changes are especially harmful to the virus. For example, the change (mutation) that most commonly makes the virus resistant to the drugs lamivudine (3TC, Epivir) and emtricitabine (FTC, Emtriva) is especially harmful to the virus' ability to reproduce. For this reason, most doctors will keep a person on these drugs, even when their virus is resistant to them.

third line therapy

A good working relationship with an HIV-experienced doctor is ideal for anyone living with HIV. This is even more vital when a person has taken many anti-HIV drugs. If you have taken many anti-HIV drugs, and your viral load is rising and/or your CD4 count is falling, then considering changes in your regimen is likely wise. The following is a roadmap of questions to consider when exploring changes in therapy.

Is the virus resistant to any of the drugs you're taking?

Resistance testing is a good place to start. Resistance tests can tell you what anti-HIV drugs may be more and less potent for you. There are several types of resistance testing and each has its strengths. Work with your doctor to determine which test is best for you, and to understand the results. For more information on resistance testing, see pages 3 and 6.

Can you put together a regimen with at least two potent/active drugs?

Once you have answered these questions, look at the list of drugs you've created. How many drugs are on the list? Can you build a regimen with at least two active drugs? If so, construct the best possible regimen; one which has the best chance of working and that you are most likely to tolerate. Can you put together an alternative regimen if the first doesn't work? Having a strategy can help you make the best possible decisions.

What if you can't construct a regimen with two or more active drugs?

Look into studies for new anti-HIV drug options. Will adding a new, experimental drug allow you to build a regimen with two active drugs? If not, the difficult question is whether it is best to wait until new drugs become available or risk trying a regimen with only one active drug.

Are you prepared for the demands of the new regimen—to adhere and monitor for side effects?

Whatever regimen you come up with, it is crucial that you take the medications regularly, as prescribed. The better you can stick to a regimen, including obeying food restriction and drug interactions, the better your chance of keeping the virus in check. For this reason, it is important to be clear and honest with yourself. Many people are better able to stick to a simpler regimen. A simpler regimen can mean fewer pills, fewer doses per day and fewer food restrictions and drug interactions. When building a regimen it is a good idea to keep these factors in mind.

Based on a history of resistance test results, which drugs appear most potent for you?

Make a list of potent drugs available to you according to the resistance test results. Consider what is known about each drug, especially side effects, drug interactions and dosing schedule. Do you have personal experience taking any of the available drugs? What possible side effects are you more willing to risk or live with? What kind of dosing schedule are you most likely to be able to stick to?

Conclusion

While the challenges of these kinds of treatment decisions can seem daunting, there are reasons for hope. Some of the newer anti-HIV drugs have worked well in people who have taken many drugs before. Two good examples are the drugs tenofovir (Viread) and enfuvirtide (Fuzeon, T20). Both of these drugs were studied and worked well in people with extensive anti-HIV drug experience. Also, there are drugs in development that are designed to work in this setting. For example, the experimental protease inhibitor tipranavir, has shown some promise in overcoming resistance to other protease inhibitors.

People who have taken multiple drug combinations to treat HIV face specific challenges. While your option might be limited by drug resistance, working with an HIV experienced doctor can help you make the best choices for you.

For a more information see Project Inform's publications, *Anti-HIV Therapy Strategies*, *Drug Resistance Tests*, *Strategies for Third Line Therapy*, and *Making Decisions about Therapies*.

Reader response form

Please consider taking a few minutes to fill this out. We are interested in learning about you and topics you would like to see in *Wise Words*. Please complete and mail back by November 5, 2004 in the enclosed envelope. Thank you.

How long have you been a reader of *Wise Words*?

- ☐ Less than a year.
- ☐ 1 to 2 years.
- ☐ 2 to 3 years.
- ☐ More than 3 years.

How would you rate the readability of *Wise Words*?

- ☐ Too simple.
- ☐ Just right.
- ☐ Too difficult.

The layout of *Wise Words* makes the information:

- ☐ Easy to read.
- ☐ Difficult to read.
- ☐ The layout does not matter to me.

How useful is the information to you?

- ☐ Very useful.
- ☐ Fairly useful.
- ☐ Not very useful.
- ☐ Not at all useful.

Do you share your copy of *Wise Words* with any other readers?

- ☐ No.
- ☐ Yes. If yes, how many other readers? _____

The article I found most useful in *this* issue was:

_____

The article I found least useful in *this* issue was:

_____

When you think of *Wise Words* at its best, the publication provides information about (you can choose more than one):

- ☐ Anti-HIV treatment strategies.
- ☐ HIV-related opportunistic infections and diseases.
- ☐ How to get involved in advocacy to make a difference in the AIDS epidemic.
- ☐ The stories of women living with HIV.
- ☐ Other _____

What specific topics would you like to read about within the next year?

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

Your age:

- ☐ 18 or under.
- ☐ 19–24.
- ☐ 25–34.
- ☐ 35–44.
- ☐ 45–54.
- ☐ 55 and older.

Your gender:

- ☐ Female.
- ☐ Male.
- ☐ Transgender, M to F.
- ☐ Transgender, F to M.
- ☐ Decline to state.

Your race:

- ☐ African American.
- ☐ Asian/Pacific Islander.
- ☐ Caucasian/White.
- ☐ Latino.
- ☐ Native American.
- ☐ _____

Your HIV status:

- ☐ HIV-positive.
- ☐ HIV-negative.
- ☐ Unknown.
- ☐ Decline to state.

If you're living with HIV, how long have you known your HIV status?

- ☐ Less than 6 months.
- ☐ 6 months to 1 year.
- ☐ 1 to 5 years.
- ☐ 5 to 10 years.
- ☐ More than 10 years.

What is the resource you use most often for information about HIV/AIDS?

- ☐ Family and friends who are not living with HIV/AIDS.
- ☐ HIV service provider who is not a medical person.
- ☐ Hotlines.
- ☐ Internet.
- ☐ People I know who are living with HIV/AIDS.
- ☐ Physician, nurses or other medical service providers.
- ☐ Printed material and publications.
- ☐ _____

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