

wise words

hiv/aids treatment
information & advocacy
by and for women

Greetings Wise Women

Welcome to the 17th of *Wise Words*! Ever heard of microbicides, a prevention tool for women? Check out pages 1–2. A few new anti-HIV drugs are available and more are on the way; look on page 4 for the news. On pages 2–3 is a brief overview of the changes that will take place in January to Medicare Part D with the new prescription drug benefit. Finally, a resource list can be found on the insert.

Although this marks the final issue of *Wise Words*, the *PI Perspective* (the journal of Project Inform) will continue to cover HIV/AIDS treatment information of interest to women living with HIV. As we stop the publication of *Wise Words*, our commitment to women living with HIV continues. Our treatment advocacy efforts continue to push for new and better treatments for all people living with HIV toward a cure for AIDS. Our public policy efforts focus on programs that serve the uninsured and underinsured, which disproportionately includes women living with HIV. And our educational programs targeting positive women will expand and flourish under an exciting new opportunity. Project Inform was part of a grant proposal that was recently funded to develop a national peer education and training program for HIV-positive women. We are giving the funds that were awarded to Project Inform to the Center for Health Training and to Women Organized to Respond to Life-threatening Diseases (WORLD), an agency

providing services and support to women living with HIV. Project Inform is thrilled at the prospects to more fully develop a women's educational program through collaboration and consolidation with these organizations.

On a more personal note, these changes bring a mix of both happy and sad emotions. There is a wealth of knowledge and experiences that I have gained while being here at Project Inform. I am honored and excited to be moving to WORLD along with the peer education grant. At WORLD, I will become the Director of Training and Education, shepherding this new program forward.

As I sat down to write this, I was filled with a tremendous amount of gratefulness. Over the past years, it was the simple emails and letters from you, the readers, who inspired and touched my heart. It reminded me that this newsletter was impacting women everywhere. My appreciation goes out to every woman living with HIV, the organizations that support positive women, and those individuals who advocate for and support women living with HIV. It is your voice and experiences that will always guide my path.

May you always find strength in each other, courage in your heart and know that you are Wise Women!

Peace and Blessings, Shalini Eddens



Microbicides: a prevention tool for women!

Imagine a gel that a woman could use to help stop HIV. What if there was a cream that could protect your HIV-negative partner? Suppose you had a vaginal ring that would release a drug slowly to reduce the risk of re-infection. What if this gel or cream or ring could also prevent pregnancy, or, let you to get pregnant with reduced risk of infection?

People all over the world are not only imagining such a gel, cream or ring, they are actually working to make them a reality. These possibilities—called microbicides—could be a reality in the next decade.

Microbicides are products that, when applied topically, could prevent transmission of HIV and other infections. Microbicides are not yet available; but once they are, they would be putting the power of prevention directly into women's hands.

What is the current status?

Products are in development that work in one of several ways: killing or otherwise immobilizing pathogens; blocking infection by creating a barrier between the pathogen and its target cells; or preventing the infection from taking hold after it has entered the body.

Scientists are currently testing dozens of products to figure out if they help protect against HIV and other STDs. Of those, five are in human trials in which thousands of women are using the products to figure out if they are effective against HIV.

Why should you care about microbicides?

HIV-positive women are some of the most vocal advocates for microbicides. They could help protect women from sexually transmitted and vaginal infections other than HIV,

which can pose an even larger danger when one's immune system is challenged. Some microbicides under development may disable HIV in both semen and vaginal secretions. It could actually give HIV-positive women a way to help protect their partners who may not use condoms.

Some microbicides may also be contraceptive, while others will not. A non-contraceptive microbicide that also protects one's partner would give positive women who want to have children another option. Finally, because women with living HIV may have different needs for (and responses to) various microbicide products, we need to make sure that positive women are involved in the testing of microbicides.

How can you get involved?

Microbicide research depends on government funding, because big pharmaceuticals are *not* investing in this research. Right now,

barely 2% of the US budget for AIDS research (only two cents of every dollar) is spent on efforts to find a safe, effective microbicide. **When we have a microbicide largely depends on how many people are demanding them.** In order for microbicides to be a higher priority, our leaders need to hear from voters that microbicides are important.

Right now, the Microbicide Development Act (MDA) is working its way through both the Senate and the House of Representatives. If passed, it will help ensure that the US government's commitment to microbicide research and development is increased substantially.

How can you help?

To help make microbicides a reality, call or email your senators and representatives and ask them to co-sponsor the MDA!

To email, go to www.global-campaign.org where you can find a ready-made letter to send or you can write your own.

To call, simply find their phone number at www.house.gov or www.senate.gov and leave a message as simple as: "I am calling to ask the Representative (or Senator) to sign on to the Microbicide Development Act. This bill can make a major difference in fighting AIDS globally."

Once you have made this call or sent that email, there are many other things you can do. Through Global Campaign for Microbicides, people around the world are working in their own communities to demand safe and effective user-controlled HIV prevention tools. At the Global Campaign website, you can:

- Find out if there is a microbicides advocacy coalition in your city,
- Sign up for our bi-weekly e-newsletter, *GC News*,
- Get information to host a talk on microbicides,
- Learn more about microbicides, and
- Order the new film, *In Women's Hands*.

the new Medicare prescription drug benefit: Part D

The largest change in public benefits in 40 years is just around the corner and it will affect 60,000 to 80,000 people with HIV nationwide. On January 1, 2006, Medicare will add prescription drug coverage. This new benefit is known as *Medicare Part D*.

If you have Medicare coverage or if you have Medicaid and Medicare, it is important that you understand this new benefit and how it will affect you. It is important that you keep and read all of the information that is sent to you from Centers for Medicaid and Medicare Services (CMS), Social Security Administration (SSA), and any of the state and local healthcare agencies that communicate with you.

Enrolling in a Medicare drug plan will be the best or only way for most HIV-positive Medicaid benefi-



ciaries to get prescription drugs. It is important that you research your options, make a decision about which plan best meets your needs, and enroll by January 1, 2006.

Medicare will offer *extra help* to low-income beneficiaries to assist with drug costs. You should apply if you think you may qualify as it can make a substantial difference in what you have to pay under the new benefit.

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Getting started:**the standard Medicare benefit**

Everyone who gets Medicare is eligible for the standard benefit. It has an average premium of \$32.20 per month. Some plans will have higher premiums, some lower. Once the premium is paid, you are responsible for a \$250 deductible before you start getting coverage for your drugs.

From \$251 to \$2,250 in total drug cost, Medicare will pay 75% of the cost; you will pay 25%. At \$2,251 in total drug cost, you reach the coverage gap, or *donut hole*. You are responsible for all of your drug costs until you reach \$5,100 (including your deductible). At that point, you reach the catastrophic coverage level and Medicare pays about 95% of your drug costs. You will then be responsible for the greater of 5% of your drugs or \$2 for a generic drug and \$5 for a brand name drug.

Medicare also offers **extra help** or a *low income subsidy* to all who qualify. People who have both Medicaid and Medicare and some others automatically qualify for *extra help*. People who do not have Medicaid and have incomes at or below \$15,000 for an individual and \$20,000 for a married couple may qualify and should apply. *Extra help* will get rid of the “donut hole” and make a significant difference in how much you have to pay for your drugs. It is very important that you apply if you think you might qualify.

Enrolling in the Medicare prescription drug benefit

If you have Medicare and get your prescription drugs through Medicaid (known as Medi-Cal in California), your drug coverage will automatically change from Medicaid to Medicare on January 1, 2006. You will no longer have Medicaid coverage for most of your prescription drugs.

If you have only Medicare and get your drugs from the AIDS Drug Assistance Program (ADAP) or pay for them yourself, you have until May 15, 2006 to sign up for the new benefit. After May 15, you will pay 1% more for your coverage for each month you delay signing up. However, if you need assistance from ADAP to cover costs associated with Medicare, you will have to sign up for a

Medicare plan before you can continue to get ADAP benefits.

If you have Medicare and another type of insurance that pays for your prescription drugs, you may sign up for Medicare Part D or keep your other insurance. To avoid the late sign-up penalty, be sure that your plan is similar to the Medicare benefit. The only way you can be sure that your plan qualifies as similar is to check directly with the plan.

Choosing a Medicare drug plan

The Medicare benefit allows you to get drugs through either private plans that will provide just your prescription drugs (known as *prescription drug plans*—PDPs) or private managed care plans that offer you health-care and prescription drugs (known as *Medicare Advantage Plans with Prescription Drug coverage*—MA-PDs).

Everyone will have at least two plans to choose from; but depending on where you live, you could have more than 40. Each plan will have a different list of drugs (*formulary*). All anti-HIV drugs will be included on all formularies. However, other drugs you need might not be. Plans will also have different costs, including different premiums (the set amount you pay each month to keep your plan), and different amounts for individual drugs. If you qualify for *extra help*, some of these costs will be paid for you. In most places, you will also have to decide if you will use a stand alone prescription drug plan or a managed care plan that also offers prescription drugs.

Information about plans will be available at www.medicare.gov in October 2005. As well, a *Medicare and You* handbook with information on plans in your area will be mailed to you. You can also call 1-800-MEDICARE for information.

If you have Medicaid and Medicare, you will be automatically assigned to a plan in October. If you don't make any changes, you will be enrolled in that plan in December. If that plan doesn't meet your needs, you can choose a plan that works for you starting November 15, 2005. You may change your plan as often as you need to.

If you have Medicare only or Medicare and ADAP, you can sign up for a plan starting November 15, 2005. However, *once you make* your decision, you have to stay in that plan for the entire year, so it is important to make a careful decision.

How ADAPs will work with Medicare Part D

Each state ADAP will make a decision about what assistance it can provide to Medicare beneficiaries. The requirements for receiving assistance will also differ by state. To find out how your state ADAP will work with Medicare, call your ADAP and ask for their policy. Be aware that the policy may not be in place yet, and ask how you can find out when it will be.

Getting Help

You will need much more information about this important and complex benefit in order to make good decisions. HIV-specific information on Medicare Part D can be found at www.taepusa.org. General information can be found at www.medicare.gov, www.medicareadvocacy.org and www.cms.hhs.gov. You can also get general information by calling 1-800-MEDICARE.

Information specific to California can be found at www.projectinform.org/org/medicare/partd.html and www.sfaf.org. Information specific to New York can be found at www.gmhc.org. Check with community based organizations and on the above websites for updates.

The Medicare prescription drug benefit is very complex. Many people will find it hard to make all the necessary decisions on their own. If possible, consult with a friend, advocate, case manager or benefits counselor. Your medical provider or pharmacist may have information on the benefit. Check for Medicare workshops in your area as well. Although it may at first seem overwhelming, it is very important to make good decisions about what plan will best fit your needs and search out additional coverage for costs you can't afford.

2005 has been a relatively quiet year on the anti-HIV drug front with only one new anti-HIV drug—tipranavir (Aptivus)—approved by the Food and Drug Administration (FDA). Fortunately, a look into the HIV drug development pipeline shows a handful of new and hopefully promising candidates in the later stages of clinical testing.

TIPRANAVIR

In July 2005, the FDA approved tipranavir, in combination with other anti-HIV drugs, for people with detectable viral loads and whose virus has developed resistance to other protease inhibitors (PIs). Tipranavir is taken as two 250mg capsules (500mg total) twice a day (total daily dose 1,000mg). It must be taken along with 200mg of ritonavir (Norvir) twice a day (total daily dose 400mg). This is twice the boosting dose of ritonavir typically used with other drugs, and it may increase the toxicity of the overall regimen. Tipranavir should be taken along with a meal. In clinical trials, tipranavir was effective in many people with PI-resistant virus, with most people experiencing significant drops in viral load and increases in CD4+ cell counts.

Some severe liver complications were seen in the same studies. People with chronic hepatitis B or C virus should exercise caution when taking tipranavir. Everyone taking tipranavir should have their doctors monitor their livers, because liver problems were seen in some people without hepatitis. Other commonly reported side effects were nausea, vomiting, diarrhea and headache.

There is concern about tipranavir's lengthy list of drug interactions, which is further complicated by the required large ritonavir boost. People taking tipranavir should work closely with their medical provider and pharmacist to manage any drug possible drug interactions. More information can be found in Project Inform's publication, *Drug Interactions*.

For more information about tipranavir, read the publication, *Tipranavir*, available at www.projectinform.org.

TMC-114

The FDA granted Tibotec Pharmaceuticals accelerated approval review for its new PI, TMC-114. It could be available in pharmacies sometime in late 2006. The company is launching an expanded access program for the drug that will begin in October 2006. For more information about how to apply for this program, call Project Inform's Infoline or watch for the announcement on www.projectinform.org.



TMC-114 is taken as 600mg once a day, along with 100mg of ritonavir. TMC-114 must be taken together with other anti-HIV drugs. Like tipranavir, TMC-114 has been shown to work in people whose virus has developed resistance to other PIs. Although it is too early to know all of the possible side effects for this drug, diarrhea and numbness in the mouth have been reported in trials.

CCR5

Another important area of research right now is in a new class of anti-HIV drugs, called CCR5 antagonists, or *entry inhibitors*. This class of drugs attempts to stop HIV from using the receptor called CCR5 to get inside the cell. Three pharmaceutical companies have CCR5 drugs entering the final phase of clinical testing. However, one drug has encountered a severe liver toxicity problem, and it is unclear whether this drug has a future.

OTHER DRUGS

Looking a bit further into the future, there are some other approaches being studied. There are other kinds of entry inhibitors, integrase inhibitors and maturation inhibitors. There are also new drugs in the current classes, such as NRTIs and NNRTIs. For a list of clinical trials in your area, call 1-800-TRIALS-A (1-800-874-2572).

These new drugs may prove particularly vital for people who have taken many anti-HIV drugs and whose virus has developed resistance. These people (*heavily pre-treated* or *salvage* patients) stand to benefit the most from new strategies to block HIV from replicating. It is encouraging to see studies being done to benefit this group of people.

Resources and Information for Women Living with HIV

REGIONAL WOMEN'S ORGANIZATIONS

California

Women Alive

Women Alive publishes a quarterly newsletter and is active in policy and treatment issues affecting women living with HIV.

1566 Burnside Avenue
Los Angeles, CA 90019
1-800-554-4876

WORLD (Women Organized to Respond to Life-threatening Diseases) WORLD provides support, information and education to women living with HIV, their families & loved ones promotes public awareness of the issues women living with HIV/AIDS face.

414 Thirteenth Street, 2nd Floor
Oakland, CA 94612
510-986-0340
www.womenhiv.org

Women At Risk

Provides emotional and educational services to women living with HIV/AIDS and their families, as well as education outreach to the communities in the greater Los Angeles area.

5183 Overland Avenue, Suite B
Culver City, CA 90230
310-204-1046
connect@womenatrisk.org

Christie's Place

A nonprofit social service organization providing HIV/AIDS education, support and advocacy to empower women, children, families and individuals whose lives have been impacted by HIV/AIDS to take charge of their health and well-being.

2440 Third Avenue
San Diego, CA 92101
619-702-4186
www.christiesplace.org

Georgia

SisterLove

A reproductive and sexual health rights organization providing education, support and advocacy to women and their families affected by HIV/AIDS.

1285-A Ralph David Abernathy Blvd., SW
Atlanta, GA 30310
404-753-7733
www.sisterlove.org

New Jersey

New Jersey Women and AIDS Network

Provides a range of support, educational, counseling and outreach activities to HIV positive women and women at risk.

103 Baynard St., 3rd Floor
New Brunswick, NJ 08901
732-846-4462
SisterConnect Warmline: 1-800-747-1108

New York

Iris House

Provides a range of services and support for women and their families affected by HIV/AIDS.

2348 7th Avenue
New York, New York
646-548-0100

SMART University

Provides treatment education and support for all women living with HIV/AIDS in order to increase their self-confidence and self-esteem.

306-308 West 38th St, 6th Floor
New York, NY
212-564-3282
212-560-6558 (infoline)
www.smartuniversity.org

GMHC—The Women's Institute

A place that honors the whole woman, where women can come together to group and support each other. Programs include, child life program, nutritional support, lesbian AIDS project, and women in action supporting women in recovery.

119 West 24th Street
New York, NY 10011
212-367-1363 (Information Line)
www.gmhc.org/programs/womens_institute

Texas

Women Rising Project

PO Box 4874
Austin, TX 78765
512-406-6150

A Sister's Gift

A community/faith-based nonprofit organization providing services to HIV positive women in Dallas and surrounding counties.

1515 North Town East Blvd #138-380
Mesquite, TX 75150
(972) 523-0815
www.sistersgift.org

Washington

BABES Network

Dedicated to building a community among women from all walks of life who are facing HIV/AIDS. They are a non-profit organization providing peer counseling, support groups, advocacy, trainings and educational forums, retreats and a newsletter.

Washington, DC

Women's Collective

A non-profit organization dedicated to meeting the needs of women with HIV/AIDS. It's services are peer-led, women focused and family oriented.

1436 U Street NW, Ste. 200
Washington, DC 20009
202-483-7003
www.womenscollective.org

Resources and Information for Women Living with HIV

NATIONAL HOTLINES AND INFORMATION LINES

National Women's Health Information Center

This government-sponsored hotline provides information on women's health issues, including HIV and pregnancy.
1-800-994-WOMAN

Centers for Disease Control and Prevention National AIDS Hotline
1-800-342-AIDS

HIV/AIDS Treatment Information Service (HATIS)

This hotline answers questions about HIV treatment and distributes the Federal Guidelines on HIV Treatment free of charge.
1-800-HIV-0440

AIDS Clinical Trial Information Service

A hotline with information about pediatric and adult clinical trials and specific trials in your area, including studies of AIDS drugs in pregnancy.
1-800-TRIALS A

Project Inform National HIV/AIDS Treatment Infoline

Mondays, Wednesdays, Thursdays 9am-4 pm PST; Tuesdays 9 am-7 pm.
1-800-822-7422

NATIONAL RESOURCES/ ORGANIZATIONS

American Foundation for AIDS Research (amfAR)

A non-profit organization dedicated to HIV/AIDS research, prevention, and advocacy.
1-800-39-AMFAR

National Minority AIDS Council (NMAC)

National organization dedicated to developing leadership within communities of color to address the challenges of HIV/AIDS.
1931 13th Street, NW
Washington, DC 20009
(202) 483-6622
www.nmac.org

Black AIDS Institute

The Black HIV/AIDS policy center dedicated to reducing HIV/AIDS health disparities by mobilizing Black institutions and individuals in efforts to confront the epidemic in their communities.
1833 West 8th Street, Suite 200
Los Angeles, CA 90057
(213) 353-3610
www.blackaids.org

For a comprehensive list of national and local organizations that have public policy and advocacy programs, go to the Project Inform's website at www.projectinform.org/org/presources.html.

NEWSLETTERS AND WEBSITES

Positively Aware

Bimonthly newsletter for people living with HIV published by Test Positive Aware Network in Chicago. Newsletter covers a wide range of health, legal, social and financial issues. They also publish *HIV Drug Guide*, with comprehensive information on all the approved HIV medications. To subscribe: 773-989-9400 or www.tpan.org

POZ

Publishes a monthly newsletter and a variety of other resources and educational materials for people living with HIV both nationally and internationally.
www.poz.com

The Well Project

Provides health information for women living with HIV/AIDS.
www.wellproject.org

AIDS meds.com

Provides easy to read, comprehensive HIV/AIDS information.
www.aidsmeds.org

National AIDS Treatment Advocacy Project (NATAP)

To educate individuals about HIV and Hepatitis treatments and to advocate on the behalf of all people living with HIV/AIDS and HCV on a local, national, and international levels.
www.natap.org

AIDSMAP

A British based organization, providing reliable and accurate HIV information to people living with HIV and their providers.
www.aidsmap.org

AIDS Education Global Information System (AEGIS)

Information & resource portal with information for HIV-related treatment, research, services & access.
www.aegis.com

Treatment Issues

A monthly newsletter published by the Gay Men's Health Crisis (GMHC) covering a range of HIV treatment information, research, public policy and advocacy issues both nationally and internationally. For subscription contact:

GMHC Treatment Issues

The Tisch Building
119 West 24 Street
New York, NY 10011
Email: ti@gmhc.org

The Body

Provides accessible information on line. Gather articles and information from numerous sources.
www.thebody.com

San Francisco AIDS Foundation—*BETA Bulletin of Experimental Treatments for AIDS* Newsletter that covers developments in AIDS treatment research; available in English and Spanish.

PO Box 426182
San Francisco, CA 94142-6182
415-487-8060
beta@sfaf.org

New Mexico AIDS Infonet

An international online resource for information on HIV/AIDS. Provides information in English and Spanish.
www.aidsinfonet.org

International Community of Women Living with HIV/AIDS

Only international network for women, providing information, support and advocacy for women living with HIV. Website is in English and Spanish.
www.icw.org