

SAY IT!! WOMEN GET AIDS.

It is estimated that one million people in the United States are infected with HIV. Because of the long incubation period of the disease, the number of AIDS cases is expected to rise dramatically over the next few years. Even if the spread of HIV slows, the number of AIDS cases will continue to increase unless early treatment strategies are developed. Epidemiologists have been charting the demographic shift of the epidemic toward women, Hispanics and blacks for several years. Women are among the fastest growing groups of newly infected persons with HIV in the United States. Women are also the most misdiagnosed, underdiagnosed and underserved population in the AIDS pandemic.

The AIDS Coalition To Unleash Power, ACT UP/Golden Gate's morals to improve the lives of women with HIV are:

- **That the Center for Disease Control (CDC) re-define AIDS to include diseases which are HIV related that are specific to women**
- **That extensive outreach be made to women to give women access to treatment and education for HIV**
- **That the Food and Drug Administration (FDA) demand that protocols for Clinical Trials be gender inclusive from day one of Phase I testing**
- **That more gender specific Clinical Trials be established to examine the affects of experimental therapeutics on women**
- **That there be, across the board, increased funding and housing for women with HIV infection**
- **That the FDA implement the recommendations of the Lasagna Commission Report and adopt a policy for faster drug approval for people with life threatening illnesses**

Of the issues confronting women with HIV, the most serious is the CDC's classifications for AIDS. A case of AIDS is defined as an illness characterized by one or more opportunistic infections or "indicator" diseases depending upon the status of laboratory evidence of HIV infection. The definition of AIDS that the CDC recognizes does not include life-threatening and debilitating illnesses which are specific to women. Pelvic Inflammatory Disease (PID), Candidiasis, Chlamydia and Human Papillomavirus (HPV) are a few of the manifestations of HIV which are specific to women. Many HIV+ women die of complications from these opportunistic infections without ever receiving an AIDS diagnosis, as these illnesses are not classified as AIDS defining.

Federal, State and local governments extend social security and medical benefits, including housing, only to those with CDC defining AIDS and in some cases AIDS Related Complex (ARC), excluding those with other HIV related diseases.

Those who frequently treat women with HIV infection say, due to the present CDC classifications that currently fail to recognize certain conditions as "AIDS-defining", the true scope of HIV illness in women at this time may be unknown. The CDC must redefine AIDS to include gender specific opportunistic infections. To improve the lives

of women with HIV they must also produce a comprehensive document on the natural history of HIV disease in women and the effects of antiretroviral agents in women must be formally studied.

Physicians frequently misdiagnose HIV disease in women as they do not recognize early symptoms of HIV disease in women, such as chronic yeast infections, severe candidiasis and other vaginal infections. Access to health care treatment and education for women is a broad social problem that is not limited to the AIDS pandemic. When these social problems meet the AIDS pandemic however, the result is fatal.

Women are denied access to clinical trials. Issues of childcare, socioeconomics, injection drug use and "child-bearing potential" exclude women from participating in clinical trials and thus denies women access to drugs which could effectively prolong their life and improve quality of life. Parallel track or expanded access is not functionally available to women infected with HIV as a primary care physician must fill out papers for enrollment and most women infected with HIV are low income. Further, Medicaid and Medical do not pay for experimental drugs or the testing that is required for experimental drugs.

It is estimated that the transmission mechanism for 56% of women currently infected with HIV was intravenous drug use. Across the board, IVDUs and substance abusers are disqualified from participating in Clinical Trials. This, of course, is another means by which women are being denied access to therapeutic agents.

The CDC has given guidelines to physicians that pregnant women with HIV should be encouraged to have abortions. On the average, vertical transmission rate from mother to fetus is about 30%. There is no substantial evidence that AIDS progresses more rapidly with pregnancy. Still, women are being encouraged and often coerced to abort pregnancy even though chances are quite good that her child will not be infected with HIV. Women should be counseled on the risk of HIV infection to her child during pregnancy but she should not be advised, coerced or persuaded in her decision on whether or not to carry a pregnancy to term. Proper education must be made available to women.

When AZT was approved as effective, with reasonable toxicity, for general use in treating HIV, not one woman had ever taken the drug. Although AZT proved to cause cervical cancer and difficulties in female lab animals, it was never tested in women before it was released for wide spread use. Toxicity and efficacy data must be provided to women prior to taking an FDA approved drug. Women should not be discovering a drugs toxicity and efficacy in post-marketing studies.

Women should be included from day one of Phase I clinical testing. Women are biologically different from men. Women with HIV need to know what the true risks associated with any pharmaceuticals or therapies are. Clinical Trials which are not gender inclusive must be considered incomplete and ineffective by the FDA. Clinical Trials must be designed to serve the needs of patients and include the needs of women. Case reports should provide gender specific questions and answers. Childcare should be provided and gender specific lab test should be run.

Currently there are only two women specific Clinical Trials occurring in the United States. Information must be gathered on an experimental drugs affects on pregnancy

and menstrual cycles and how a drug reacts specifically with women's biological make-up. While community based research groups are for the most part pioneering the efforts of gender specific Clinical Trials, the AIDS Clinical Trial Group (ACTG) must adopt these types of trials as a policy.

As the AIDS pandemic progresses, it is clear that increased funding and housing must be made available for women with HIV disease. 50% of women in San Francisco who are HIV+ have been homeless at some point during their status of HIV positivity. Clearly the CDC classification for AIDS plays a direct role in the limited funding available to women with HIV. This is wrong. Financial and material assistance must be provided to women with HIV disease.

Faster drug approval for people with life-threatening illnesses is essential for women and other minorities to obtain access to drugs and therapies which could save their lives. The FDA must implement the recommendations of the *Lasagna Report*.

The issues which confront women with HIV infection are broad and varied. There are cultural issues of access to health care which confront women of color, who are the highest population of women currently affected by the AIDS pandemic. There are issues of cultural differences and religious imperatives which hinder access to information to Latina women. There is a profound lack of information on woman to woman transmission of the virus, though there are reported cases of Lesbian transmission. There are social conceptions that women are vectors of disease and there is a tendency to treat a fetus rather than a woman. These issues are no less significant than any other issue discussed.

Women die of AIDS faster than men. The average life span for white men from the day of AIDS diagnosis to death is 24-36 months. The average life span for women from diagnosis to death is 15 weeks to 6 months. The average life span for a black woman in New York from diagnosis to death is approximately 15 days. The risk of infection is 14 times greater for a woman exposed to HIV for the first time than it is for a man. It is easier for a man to transmit HIV to a woman than it is for a woman to transmit the virus to a man.

The most important issue facing women with HIV infection, however, is the CDC classifications for AIDS. SAY IT!! WOMEN GET AIDS. Until AIDS in women is recognized and researched more extensively, it is virtually impossible to deal with the other issues which confront women with HIV. Women are invisible in the AIDS pandemic. This is wrong. Women get AIDS. Women die from AIDS. Women are being ignored in this pandemic. Effective treatment for women with AIDS cannot be fully established until the CDC acknowledges and reports on how women are being affected by HIV.