The Consensus statement and the CDC Transcript/Commentary

"Our position comes from our history of work to change the definition. In November, 1989, women activists met for the first time with Dr. Curran to discuss updating the 1987 definition to be more representative. He suggested at that time, the use of 200 T-cells to add to surveillance, but he was not open to adding additional clinical manifestations. There followed a series of demonstrations, discussions, public meetings and general pressure. AIDS activists launched a national campaign that raised awareness world wide that women were getting AIDS and falling thorough the cracks of surveillance and health care. The first demonstration was held in Atlanta in February 1990, in June of 1990 another action occurred at the international conference in San Francisco. On December 1st, 1990 "World AIDS Day", more than 300 activists, mostly living with HIV, and mostly women stood out in the pouring rain, chanting and marching, locked out of the CDC. 96 people were arrested. In late December of 1990 the government sponsored it's only National Conference on women and HIV in Washington D.C.. The overwhelming majority of attenders at that conference supported adding women specific manifestations to the definition and Dr. Curran's speech was challenged by women living with HIV. In June of 1991, the call for the immediate revision of the CDC AIDS case definition was issued, demanding that a list of 13 manifestations in women and Injection Drug Users be added to the definition. That call and it's more than 500 endorsers was placed in a New York Times ad to coincide with the 7th international AIDS conference in Florence. At the same time there were discussions happening throughout the country on women and AIDS. When CDC representatives came to San Diego in late 1991, ACT UP/LA rose to the occasion and they were there to question Dr.'s Noble and Curran. They held up banners and called for all women in the audience that agreed that women specific illness should be included in the AIDS definition to come to the front of the room. 57 women got out of their chairs and stood at the podium in solidarity, united with activists on this issue. In November 1991, CDC issued a proposed revision listing only 200 T-Cells as an added condition. The CDC's blatant exclusion of diseases that affect women and IDU's has resulted in this delay that we have all endured in the struggle for developing a more accurate AIDS definition. The CDC received numerous responses to their proposal and subsequently became open to further discussion. At the same time the Congressional Women's Caucus, the National Commission on AIDS and even the American Medical Association called for an expansion of the AIDS definition. In April of this year we learned that James Mason was about to sign the 200 T-Cell recommended revision. Due to activists pressure once again it was not signed. In an attempt to move forward, a women's coalition effort was initiated and Dr. Curran agreed to meet with activists on the proposed changes and time lines for implementation. We do not have the time line yet, but we do have this public meeting . The reason to site all this history is to say that the consensus is here, and we can't wait any longer for an expanded AIDS case definition." The Coalition Consensus Statement Is: The Surveillance Definition of AIDS must be expanded to include the following conditions when found in the presence of HIV infection. #1) Cervical Cancer. #2) Pulmonary Tuberculosis. #3) Recurrent Bacterial Pneumonia. Without modification of the definition to include these additional conditions, countless individuals will continue to become ill and die without ever receiving an AIDS diagnosis. **To the extent that CD-4 counts below 200 will confer an AIDS diagnosis the CDC must require that such tests be accessible without regard to ability to pay, be processed through only labs which satisfy quality control conditions and that results be anonymous and or confidential, including a ban on the direct reporting of CD-4 cell lab test results from laboratories to state and local health departments.** The conditions of this statement represents a compromise by people living with HIV, activists, community based organizations and clinicians who have been working for an expansion of the AIDS case definition for more than two years. We chose these three conditions in an attempt to satisfy the CDC's concern that only illness with an established link to HIV and with high rates of morbidity and mortality should be included in the definition. We chose these three conditions out of our original list of 13, because despite the CDC's double standard, we have the most thorough documentation on the three listed. **The coalition does not accept that the inclusion of 200 T-Cells will result in an accurate enough surveillance. Many of us continue to have reservations about the exclusion of other conditions and we are convinced that what constitutes AIDS is more than 26 illnesses.** However, we propose this consensus statement because time is of the essence. In an effort to move forward the coalition offers this consensus statement in it's entirety as a workable solution to the stalemate on expanded surveillance. We look forward to a productive and representative definition."

The **opening session on surveillance** continued with a CDC spokesperson saying: "We all recognize the need for expanded surveillance. However, there are diverse opinions on the most efficient and beneficial guidelines for this expansion. Still everyone in attendance has one thing in common, the dedication to the prevention of the spread of HIV and dedication to helping to provide the best information and services for those already infected. We are here today to hear what those in the community have to say about the expansion of this case definition.

We all agreed on what surveillance is and that the goals and purposes of surveillance include measuring effectively, the changes, trends, magnitude and nature of the HIV epidemic, and further it provides a way to standardize and interpret data. The surveillance definition should serve to identify HIV illness associated with morbidity and mortality. And that the surveillance definition should incorporate the most current diagnostic practices. We agreed that revisions should be considered with the objective of achieving a more accurate representation of the numbers of immune suppressed persons. "WHERE TO DRAW THE LINE IN THE COURSE OF THE INFECTION FOR AIDS SURVEILLANCE WILL BE DETERMINED HERE TODAY." CDC personnel and surveillance officers argued that the inclusion of 200 T-Cells would adequately expand surveillance. "This expansion will provide simple and direct reporting as well as an objective measure of the numbers of persons with advanced immuno-suppression. This approach will eliminate the logistically implausible task of developing a complete list of HIV associated diseases. The 200 T-Cell expansion would be useful because it would lead to case reports from a greater number of sources, such as laboratories and outpatient clinic settings." The surveillance officer from Los Angeles, Peter Kermdt, expressed his concern that adding OI's would increase the volume of his paper work and perhaps become unmanageable and even risk accurate surveillance reporting. Most surveillance officers agreed that adding three more diseases to the existing 23 AIDS defining OI's would increase their workload, increase the volume of their paper work and make their jobs more difficult and cumbersome. **Where as adding 200 CD-4 counts would simplify their task because reporting would come directly from laboratories to health departments.**

Dr. Christine Reyelt from New Jersey challenged this position by suggesting that it may become necessary to expand the staff of surveillance officers in order to accomplish our goals. That a variety of clinical manifestations in HIV must be included in surveillance. "If you find defining AIDS to be difficult, treating it is even more difficult, and having it is intensely difficult beyond both of those." The coalition: "Currently the CDC is not meeting their mandate to track the epidemic. Simply adding 200 T-cells would not correct this problematic flaw. The use of CD-4 counts to provide an AIDS diagnosis is bound to result in an undercounting of persons with severe HIV related morbidity and mortality, because individuals do not receive CD-4 cell tests unless their health care provider already suspects underlying HIV infection. The proposed T-Cell inclusion in the definition would not accurately trigger the question of HIV infection and the case count will remain incomplete and artificially low because women and IDU's get severe HIV disease and die at higher T-Cell levels (300-400 range). Since the formation of the AIDS definition and with every subsequent revision, the CDC defined AIDS by listing illness found in young gay men from clinical observation. **Now there is a double standard for women!** Now the CDC has upped the anti, requiring a higher level of proof for women and IDU's. This more stringent prerequisite for inclusion has resulted first in a failure then in drastic delays to fund and conduct studies in women. It is striking that the CDC which has seen fit to provide a definition with 23 opportunistic infections would animately draw the line on including in the definition the few illnesses that particularly affect women and other disenfranchised HIV+ persons. The fact that CDC has chosen to draw the line here creates an appearance of underlying racism, classism, and sexism that is only thinly veiled by scientific theory and rhetoric. This not only precludes women and IDU's from access to healthcare, it has a profound impact on surveillance accuracy."

Clinicians comment: "**Surely nobody here is naive enough to think that T-Cell counts under 200 is a specific prognosticator.** We all have patients who have T-cell counts well over 200 who are sick and some are dyeing. On the other hand, for as long as we've been measuring T-cells, we've all seen people with counts well below 200 remain healthy for significant periods of time."

Moderators: "Our next speaker will present an **individual perspective:**"

"I've waited over two years for this opportunity, two years, more often than not, for a woman living with HIV/AIDS in America is a life time. In this the second decade of AIDS it is ludicrous that we are still discussing that HIV manifests itself gynecologicaly in women. How can anyone be so absurd as to say that pelvic Inflammatory Disease, that occurs every time that a woman menstruates, with pain so bad that when it's happening she faints, is not debilitating enough to be considered to be life threatening? In 1986, I had a yeast infection that became so aggravated that my clitoris was so swollen that it hung below my vaginal lips. There was no physician that could give me comfort. I now get vaginal yeast infections every month. They are not the kind that you see those pretty women comfortably sitting on couches advertising for over the counter brand cures. Mine are so severe, I cannot sit, stand or lie down comfortably. The itching and burning becomes so intense that I cannot sleep and if I do fall asleep, I sometimes scratch myself, which leads to other infections that are generally treated with antibiotics, that give me the yeast infections again. I find it suspect that although vaginal yeast infections have been around for ages...precisely at the time that female AIDS activists began to apply pressure to CDC to get the word out that chronic vaginal yeast infection was a sign of HIV infection in women, pharmaceutical companies suddenly came out with an over the counter cure. Now women could quitely cure themselves, at home, alleviating the responsibility of the medical community, and letting the CDC off the hook. It makes sense to me...think about it. Between 1984 and 1987, I had six hospitalizations for recurrent bacterial pneumonia. Two of those coupled with endocarditis again. In 1988, I presented with cervical dysplasia. I want to note here that on each one of those hospitalizations, I was discharged. I was also homeless, actively an intravenous drug user and selling myself by having unprotected sex in exchange for my drug. No one ever bothered to ask me to get tested for HIV. In 1990, I had to have a hysterectomy due to cervical cancer. The day of my hysterectomy, I was finally diagnosed "HIV Positive". The only reason I was tested is because I told my surgeon that my ex-boyfriend had tested positive a month before. I am in no way unique! Recurrent bacterial pneumonia, cervical cancer, chronic vaginal yeast infections and pulmonary tuberculosis, are more common than not in HIV positive women. ... IF I, A LAY PERSON, KNOW THIS?, THEN HOW CAN THE CDC WHO SET POLICY FOR THIS ENTIRE NATION NOT KNOW THIS? ! ? The horror of your neglect is that unfortunately, other countries throughout the world use the CDC definition for an AIDS diagnosis. Common sense tells you, if your definition is based on tests done primarily on men, then women who's internal organs are entirely different will present with different diseases. The point is that women are being treated and discharged. The result of that indifference on the part of the CDC is at the very least a co-factor in the continued spread of HIV infection in the United States. But the CDC can accept the full blame for the swiftness with which women die once they are diagnosed, since they largely go untreated and undiagnosed until death. How long? is my question. How long will women continue to die literally on the streets of every city, county and town...and on the roads of our rural and farming communities, in the mountainous regions? How long, I ask you, how long must our native American women suffer on reservations without getting help or proper treatment, because we ALL go undiagnosed!! Women are not some "pop-cult group" or a "special population". We are an integral and vital part of humanity, equal and necessary. How long must the women of America be expected to support a government that ignores us?, finding our complaints not important, and our diseases not life threatening enough? How many of us must suffer needlessly until the CDC allows the definition to include those diseases that are specific to women??? It's strange to live in a country that first, due to my race, then my gender, my economic and now my health status, considers me unnecessary. Your message seems to be that "We'll let you all talk and then hopefully, you'll get tired enough and sick enough to be quiet!" Well, let me tell you, THINK AGAIN.!! My HIV positive sisters and I will continue for as long as it takes to be a visible and vocal lesion in the side of CDC policy makers until we are treated equally, by having our lives and our health considered as important as those of men. I leave you with these words...So that every time you hear my voice or see my face, you'll know that I am holding YOU accountable and YOU responsible for the unnecessary suffering of women the world over!! And I will not distort my voice, I will not cover my face and I certainly will not live the remainder of my life hiding in shadows.! ! ! My name is Wendy Alexis Modesty, and I am a proud Afro-American Woman, who despite the CDC is LIVING with AIDS is Syracues, New York.

There was a separate and distinct panel to present arguments and data in support of or against inclusion of each proposed O.I. for AIDS surveillance purposes. Each panel had an HIV+ woman who was allowed to give her personal perspective and therefore create a mechanism for a "reality check" on the decisions that directly affect their lives and the survival of all people living with HIV/AIDS.

editorial comment: All the positive women were united in their message that they are living the reality of AIDS and that they are angry about the double standard expected for women's inclusion in the AIDS definition and all expressed disdain towards the CDC for playing politics with their lives. (all but one) They gave each other standing ovations, re-assurance and support. They spoke from the panels, they spoke from the podium and some took the opportunity to speak from the open microphones in the isles. There was suspicion that all of this might just be a "set-up", a hoax, so the CDC could say "OK, we let you have your say, but we are still not convinced" A kangaroo court!

The **panel on Pulmonary Tuberculosis** resolved in an unanimous collective opinion that indeed pulmonary TB with co-infection of HIV should be added to the list of AIDS defining Opportunistic Infections for surveillance. Irus Long from ACT UP/NY presented a real life case scenario of a Latina who couldn't get the right medications for Multi-Drug-Resistant TB, because they were not legal in this country. So instead the woman was forced on a regiment of 42 pills a day for two years, yet she relapsed again and again. There was no effective treatment out there for her. All panelists presented conclusive data that TB, in the presence of HIV, is quite different than ordinary TB and must be treated differently.

The next **panel** discussion was on the inclusion of **Recurrent Bacterial Pneumonia:** The panel opened with a woman saying: "The impact of the decisions from this discussion we have here today are going to have a profound impact on the epidemic. I'd like to speak from the perspective of another group of people who have been in the fight against AIDS for as long as the epidemic has been with us. We built programs form nothing. State people who have far exceeded the national response, and community level groups which have preceded the states. So, we have representatives from communities, states, and national initiatives coming together here. And now finally we are looking at the possibility of real change. The other thing that we developed from coming together as a National Alliance is solidarity. This epidemic has gone from urban to suburban and rural. We've been calling for timely action needed to expand the definition and it is too late already. The overall picture of AIDS is much greater, much more devastating and has a greater impact on peoples lives throughout the country, than CDC and Congress have been willing to address to this point.„

Peter Selwyn on Bacterial Pneumonia: "Recurrent episodes should unquestionably be included, and perhaps a single episode should qualify as well, when coupled with a single incidence of a additional manifestation. This would enable us to further capture the impact on mortality and morbidity."

Every one on the bacterial pneumonia panel was very much in favor of including it in the revised case definition: They presented data on morbidity that occurs most often above the 200 T-cell cut off, more often in the 400 range. Presenters agreed that the definition of a syndrome is not something we revise once and then leave alone...but that we must continue to make changes as we learn more about the disease.

Keri Durran, from **ACT UP/Boston:** "I am a person with AIDS and I've recently recovered from a bout with bacterial pneumonia. It was one of the most miserable experiences of my life, but never the less, it takes second place to the cab ride on the way over here. Although pneumonia due to PCP is a most common pulmonary infection associated with HIV, pneumonia caused by bacteria are also very common. Current and former injection drug users are at increased risk for bacterial infections. These diseases do not occur frequently in women who are not HIV infected, and they should be noted as indicator diseases for HIV. AIDS patients will be missed in the official national count if we are not first seen by physicians and second if the physician mis-diagnoses our symptoms. Right now those of us being excluded have little or no access to health care, including drug rehabilitation. We do not have primary care physicians or access to expensive testing. Due largely to institutionalized racism and sexism, in this country, both economic and otherwise, a disproportionate number of women mostly Afro-American and Latinas are infected and going untreated. We do not have access to private health care. We have to use public health care systems, when necessary and if they are available. Many of us do not seek healthcare until we are very ill. It is essential that the true scope of this epidemic be recorded, and indicator diseases affecting all people with HIV/AIDS are recognized and represented in the CDC definition of AIDS"

The session continued with clinicians also reporting that gay men of color are getting bacterial pneumonia with the same frequency as IDU's. A surveillance officer from Denver re: "spectrum of disease study" in defence of 200 T-cell inclusion only. The panel, however, was clear on the fact that we should not make national policy based on the spectrum of disease study alone, and that indeed national policy was under consideration here today.

The panel on Cervical Cancer was next. This panel was probably the most divided on whether or not to include the O.I. in the definition. It began to look more and more like a "set-up" when the CDC introduced Missy LeClaire as one of the co-moderators and also a woman with AIDS. She was allowed time to qualify and opened the panel with a 12 minute monologue. Missey is employed by the CDC and has access to the best possible health care. Missey did say that she thought that cervical cancer should be included as part of the definition of AIDS. She was diagnosed with dysplasia and her doctor said that what had developed in her body in the period of 6 months would have taken 15 years in an uninfected woman. But she preached to the other women that in order to deal with AIDS you have to learn to live with it. You take life one day at a time and she said: "When the lord gives me lemons, I make lemon aide" She said there had been a lot of anger in that room and that we shouldn't be angry with the CDC, that this is not all their fault, that we should be nice and polite, that we should seek out the good doctors on our own. She stated that in her opinion we shouldn't be mad and we had very bad attitudes of thinking that the government should fix things for us. She repeated that we should get past our anger and work together to include women so they are treated better and helped more. Then she went into how great her own doctor is and how he just calls the NIH to help with decisions about her care. "So, I think a lot of this is about having good physicians and that's the issue we should be looking at. I don't think anger is appropriate. It's not going to make you better, it's just going to make you sicker. So, I've decided to use my energy in a different way to bring out the positive parts of what's happening in this epidemic and what can be done to make things better"

Panelists presented data on cervical disorders in women. The representative from the American Cancer Society confirmed that Cervical cancer is NOT common in the uninfected population. Her presentation adequately addressed the CDC's position that diseases that are common in uninfected women must not be included. The data presented on women with HIV was scarce and somewhat complicated by other co-infections. Although clinicians and physicians are finding HPV and cervical warts many did not have the funding to do colposcopies, biopsies, or cultures necessary to type the HPV or complete their diagnosis. One male gynecologist stated that he strongly indorsed the inclusion of Invasive Cervical Cancer in the AIDS case definition because it would emphasize the fact that women get AIDS. But then he compromised his position by saying they didn't know enough to warrant the inclusion of dysplasia. And that including it, might result in over treatment. **Mary Lucey** was the 8th panelist to speak...the following is the content of her speech. As always, Mary put her heart into her presentation and delivered the speech with courage and conviction. (See attached)

Mary was not allowed to complete her presentation without being, first interrupted and warned of time constraints from CDC panel moderators and second having the microphone actually turned off in the middle of a sentence. It is curious to note that the microphone was cut off at precisely the point when she mentioned the responsibility of the Bush administration. Of course, when the microphone was cut off, it was not without incidence. Mary contended that she was an invited speaker and that she had come a long way to make this presentation: "You people don't know what goes on in our communities, You have no idea what we have to deal with living with this disease, and you have the audacity to turn the microphone off??? This is obvious censorship!" I, of course, was livid and could not contain myself. Even though Missey had said that we should be nice girls and not get mad and just make lemonade...I still was beyond rage. (Although, I would have preferred to have said something as eloquent as : 'We know our words are harsh and our accusations are pointed; But, you must look at the reality of the lives of women who are sick and dyeing from HIV disease to understand where these sentiments come from.") However, I am not one who is prone to be eloquent or poised in a volatile situation. So, instead, I flew out of my chair and shouted at the moderators to turn the microphone back on. The infected women in the audience responded with shouts of : "Have your say !" and "Keep going Mary! Do it for all the infected women!" and a chant of "Let her talk" emerged from different corners of the room. Mary was not stepping away from the podium. Still enraged and waving my arms, I stood in the front of the room and addressed the audience: "Does everyone want to hear her out?" An enormous response of applause indicated "YES". Then the moderator had the nerve to whine: "We can make a choice here. We can let her go on and then we won't have any time at the end for discussion or we can save time for discussion after the panel." The women shouted to let her finish and the microphone was indeed turned back on and Mary's speech in it's entirety was recorded as part of the official testimony for consideration of CDC expanded surveillance of AIDS.

The final cervical cancer panelist was Dr. Spence: "Although there is a lot of information that we don't know about the progression of this disease the data are very

clear: The disease does progress at a more rapid rate, in the HIV infected person than in their HIV negative counter part. Also the disease appears to be more severe and spread rapidly once it does invade. Based on this, I am a very strong advocate of incorporating Invasive cervical cancer into the AIDS defining illnesses. But taking it even further, into saying that we can gain useful information by paying closer attention to our patients provide a better quality of care for them and make a major public health significant impact on persons with HIV, by incorporating CIN of a higher grade into the AIDS defining illness. The disease does appear to be different, there are probably co-factors, maybe HPV, maybe drug use. There are probably a lot of things that we don't know and need to learn about this disease, and this will only be determined by conducting appropriate longitudinal studies. However, at this point in time, it is perfectly clear to many of us who are taking care of large numbers of women that this disease is distinctly different in the presence of HIV infection than in the non infected counterpart. And for that reason we should view it differently and we should incorporate it into our diagnosis of AIDS. Thank you."

Moderators: "Because time is of the essence, we'll take comments and questions for 10 minutes." I was the first one to the microphone again and said that my comment was that I was extremely offended that the microphone was turned off while an HIV infected woman was speaking "Just because you don't agree with her politics, doesn't mean you shouldn't let her speak" I thought that an apology was in order.(Wrong!) Instead the moderators got defensive and denied that any one sitting up there had anything to do with the microphone going off. (but everybody saw them give the signal to "cut" did they think we would believe that they were experiencing technical difficulty ?) It was actually Dr. Ward who threw the switch and Dr. Curran who eventually ordered it back on. We said that we found that hard to believe and took issue with the fact that everyone else at the podium that day with few exceptions had gone well over their time limits, yet only Mary had the microphone turned off during her presentation. So, we moved on and **Dr. Judith Cohen** approached the mike. "I am quite aware that I was proposed for a panel and I was refused. I'd like to say a couple of things about the epidemiological studies presented. (re: "spectrum of disease study"...original data base of 4,000 people with only 200 women. Most women in this study do not get pelvic exams or pap's because it is not a requirement of the study and only a few sites were collecting this type of data on their own.) and I would question or rather, I am convinced that this kind of epidemiology has no use for us. Because the majority of infected women never get pap's or have access to them, let alone one every six months. What we do need is good accurate thorough and complete descriptions of women's circumstances and we are not any further along on that than we were when many of us were present when this discussion took place in December of 1990. We were assured then that natural history research was at the highest priority. We were assured then that funding would be made available from

NIAID. We were assured that there would be a request for applications for proposals issued in a prompt fashion. We are still waiting for that in late 1992 to be issued and we can't even compete for it. And yet, the money is there to put towards that effort. So, we can't answer questions that require longitudinal observation. And we're not going to be able to at the rate we're going! The other comment I have is that extrapulating information from experience with men or from experience with people who have access to care is not a very good predictor of what we don't know nor what we're liable to find out. To make a particular example quite clear, one of the physicians on the panel expressed concern of misclassification, by which he meant, no consistent diagnostic standard for CIN. His argument is week. And his statement that if it is added to the definition it would result in "over treatment" is absurd. Never, in my experience or in that of any of the people that I work with in this epidemic, have we seen women who are at highest risk for AIDS, be OVER treated. They can't even get abortions when they want them, much less regular pelvic exams an accurate diagnosis or treatment." Audience participant: "I'd just like to say that one of the major problems in relation to gynecological problems, one of the biggest issues I'm finding in our local GYN's in an extremely high prevalence, is that they don't think that HIV could be involved. Specifically in the woman that is infected and doesn't know it. They don't think when they see recurrent vaginal candidiasis, they don't think when they see cervical dysplasia. They don't have a thorough enough picture to think to check her for HIV infection and I think that would give us even better data than we're getting now, because, now we're only looking at people who are already identified. And when people are unaware of their status one of the tragic things that happens is that they often unknowingly infect others with HIV and the stemming of transmission is a very important reason for linking these illnesses with HIV infection. Ken Noller, gyn: responded from the panel: "It's true that we, gynecologists have relied on our infectious disease colleagues for too long to take care of this problem. We need to get more involved. Absolutely!" **Terry McGovern:** "We do know some things about cervical cancer and I do implore the CDC to recognize the benefits that will occur in adding this condition. It's not just an access to health care problem. People with access are not getting gynecological care. It's not going to make surveillance any more difficult to add this and the benefits are absolutely incredible. Just for the record, I implore the CDC to add Cervical Cancer to the list of AIDS defining illness."

Confidentiality and informed consent issues.

The CDC is in favor of name reporting by CD-4 test results and claims that there are safeguards in place to protect confidentiality. CDC did not express a clear understanding of the impact of discrimination on the lives of individuals with HIV nor did they seem to be concerned that this type of reporting would result in large scale breached confidentiality. A woman surveillance officer remarked that there is already name reporting in many states and they have managed to effectively keep them confidential, because they are real careful not to leave these files on their desks and stuff like that. (I feel so reassured) People from different states talked about their particular restrictions and how they are prohibited from disclosing peoples HIV status, but not necessarily restricted from reporting names along with CD-4 counts unless it's couched in some inclusive language such as "indications of HIV" or something like that. **However, in the reality of TB/HIV cross reporting or exchange of information regard to privacy issues in terms of discrimination in housing and jobs are in fact real consequences of this type of reporting. Shared information or name reporting must be done in a careful and responsible manor.** CDC again expressed confidence that procedures for protecting confidentiality are sufficient. That it's already effective and that health departments have a long history of involving laboratory reporting for surveillance of many conditions and that their track record is good in this respect.

Sharon Lund was the infected panelist invited to speak on behalf of the community (Sharon will be submitting the written version of her testimony. However, I will attempt to highlight the issues for the sake of this report)

Sharon first expressed distress and frustration with how long it has taken us to acknowledge women in the AIDS epidemic and the fact that thousands of women have died suffering , silently, and alone in the process. **People with HIV/AIDS are repeatedly judged, pre-judged and treated with animosity or pity because of government neglect in their educational efforts of AIDS. Now confidentiality is threatened again with laboratory test reporting of AIDS.** "Despite government neglect, we've learned a lot about women and this virus. The first thing we've learned is that we cannot rely on our government , we need support that never comes from an ignorant society, we need early diagnosis and early treatment to combat the virus and we've learned that breached confidentiality causes discrimination and that the threat or fear of disclosure through name reporting discourages people from getting tested or seeking care." Sharon articulated how **laboratory test reporting of CD-4 counts would open many new avenues for breached confidentiality and that it would increase the likelihood of disclosure which would make people with HIV more vulnerable to discrimination in housing, jobs, schools, and social settings. She stressed again that we already know that when people fear reporting or disclosure they do not seek testing. An essential**

component of this proposed expansion is to ensure that CD-4 testing is available and anonymous. "There is one thing that all of us who are infected with this virus have in common, we all need assurance of confidentiality: "Confidentiality is the cornerstone of the fortress that protects people with this virus from discrimination." She shared her own experiences of her own friends and co-workers being afraid (because of lack of accurate knowledge) to sit next to her, share her glass, etc. and that when her gynecologist found out her status he refused to continue to treat her. She gave heart wrenching examples of the extreme damage caused by discrimination based on ignorance...damage to lives that already are complicated with health concerns of HIV disease and shortened by AIDS. She brought to life the reality of discrimination caused by disclosure or breeches of confidentiality. She told policy makers to stop burying their heads while we burry our mothers, our sisters, and our children.. And she reminded them that it is their responsibility to ensure confidentiality. That perhaps they might take this issue a little more seriously and a little more to heart, if they themselves, if only for a brief moment had to experience, first hand, the devastation and despair, the isolation and the shame that results from ignorance, bigotry, and discrimination and what a very damaging and wounding experience that is. Perhaps only then could they understand why, in a world of health care concerns, statistics, morbidity and mortality rates, confidentiality is a top priority. Things are not changing out there for women. Women need the CDC to respond NOW, not next month or next year or in five years, people with HIV/AIDS don't have that time. This is a critical time in our lives and the decisions made here today will have a profound effect on our lives."

The **closing panel** wrap up session was headed by James Curran. Dr. Curran echoed Sharon's concerns saying: "We must do what ever is necessary to protect the confidentiality of people with HIV infection." He expressed particular concern for the children. Saying that discrimination is a reality for these individuals. Well, Dr. Curran did not exactly say that he would recommend the consensus for expansion. He did say that he would consider recommending it. As far as a time line...well, it's the same as it was three years ago "in a prompt fashion". We had to leave to make our flight, so there were no activists left to actually pin him down to a date. We know that the dead line for written input was September 18. We do not know what the result of this public forum will be, yet.

It was an inspiring phenomenal and empowering experience to see the women standing up for themselves and standing up for each other and presenting a unified position in solidarity and taking on the AIDS policy makers at the highest level of AIDS policy making, perhaps, in the world. There was about 2% to 5% male

participation in the entire hearing. One CDC official said: "The only thing that hasn't been mentioned here today is 'homophobia'". We found this statement to be insulting in that he was making light of our concerns. We had called them classist, racist, sexist, and bigots. It's not that we want more people to get an AIDS diagnosis. We just want all the people who are disabled from severe HIV disease and all people who die from complications due to AIDS to be counted. Because the more of us they count the more money has to be allocated for research, treatment, direct and social services. Including more Ryan White Care funding for all people with HIV/AIDS including women, including Injection Drug Users, and including gay men. Make no mistake: This is an AIDS Community Issue. One thing is for sure.: The CDC now has no doubt that the women are spear heading this effort, that we are united, and we are not going to give up or go away until our concerns are adequately addressed and acted on. **Linda Merideth boldly acknowledged that it was the AIDS ACTIVISTS that came before us who paved the in roads for community involvement on AIDS policy making . That it was grass roots activism that brought us to this point. And that without angry people in the streets we would not have come this far. If not for ACT UP, we would have no mechanism to voice our concerns. Women with HIV/AIDS will no longer be silent. Silence = Death.**

ACT UP ! ! FIGHT BACK ! ! FIGHT AIDS ! ! **respectfully submitted by, Nancy MacNeil**