Transcript of Meeting at Centers for Disease Control, Atlanta,Georgia, November 19, 1990, 3:30p.m. - 6 p.m.

Attending: Maggie Hasbrouk(ACT UP,Atlanta), Katrina Haslip(Lifeforce), Tracy Morgan (ACT UP/NY), Chip Rowan (ACT UP/ATLANTA), Maxine Wolfe (ACT UP/NY) Gary Noble (Deputy Director, HIV,CDC), Ruth L. Berkelman (Chief, Reporting and Analysis Section,CDC), Mary Guinan (Special Assistant for Evaluation,CDC), Jacob Gayle (Special Assistant for Minority HIV Policy Coordination, CDC), Peter Drotman (Center for Infectious Diseases, CDC), Bert Petersen (Women's Health and Fertility, CDC), Bill Para (Operations, CDC).

In the transcript:

US: refers to any one of the people from ACT UP or Life Force

GN refers to Gary Noble

RB refers to Ruth Berkelman

BP refers to Bert Petersen

MG refers to Mary Guinan

None of the other people present made any comments

The meeting began with a presentation by Katrina Haslip, Tracy Morgan and Maxine Wolfe. Katrina described the opportunistic infections she and other women are experiencing, based on her role as a peer educator at Lifeforce and her previous work with ACE. She also discussed the leadership role that the CDC has in terms of the definition of AIDS and how the use of their definition by other agencies on the local and Federal level is their responsibility because these other agencies cannot do their own epidemiology and look to the CDC. For this reason, many women are being denied benefits and access to treatments and trials. Tracy Morgan presented the research evidence which supports Katrina's experiences. This evidence was from major medical journals (JAMA, Lancet, New England J., etc) as well as from doctors who are seeing large numbers of HIV+ women. Infections and diseases discussed included gynecological infections such as PID (Pelvic Inflammatory Disease, HPV, Cervical Cancer and Vaginal Thrush. She gave them a copy of her bibliography and of ME FIRST, a booklet she helped put together for the NJ Women and AIDS Network, which actually described women's symptoms. She described the process of compiling the references and the fact that, due to the CDC definition, entering "Women, AIDS" into a Medline Search only gives you references to prostitutes and pregnancy. She had to find information on immunosuppression and indicator diseases in a different fashion. Maxine Wolfe discussed why the CDC's epidemiology had gotten us to the point where women are dying without a CDC AIDS diagnosis and brought up issues of artifically lowering the scope of the epidemic, the problem with "risk groups" rather than transmission routes, the issues of mandatory and "routine" testing, contact tracing and partner notification as methods which have been proven not to work as prevention and the need for clear information, education, prevention and natural history studies, standards of care, and so on. After the presentation there was a discussion between CDCpersonnel and ACT UP representatives which is transcribed below:

GN:....(lost part of first sentence)there are reasons why they are not, but we have to work to make sure that they are as accurate as possible. I'm proud to be at CDC. I'm proud to have collegues like these people. Ruth works in AIDS clinics; Peter works in AIDS clinics; and Mary, I think many of you know her history. If anyone keeps us hones, Mary will. She's an activist. And Jacob Gayle you know. I'm sure there are a lot of things we could have done better but at least let us start with an understanding that there isn't homophobia and sexism (in response to something said in presentation). It may be part of the culture that we come from makes it impossible to escape but at least I feel good that at the CDC I am surrounded by people who work their butts off trying to do everything we can to prevent new HIV infection and to the extent that it is our mission at the CDC, which is limited, to make sure that people with HIV infection have access to care. You've raised an awful lot of questions and its hard to know where to start but, by the way, let me say that Tony Novello is certainly interested in this issue. She spoke at a conference that we had on drugs and HIV infection and...(US: she's going to be speaking at the UN)... she's also speaking at the United Nations and L've had a chance to look at a draft of her speech and I think its excellent and she is committed to taking this on as one of her own personal interests. The point I was going to make is that, at our conference on drugs and HIV infection, just this past Wednesday, was just one of the points

you made, that women do have a right to have children. Having said that, Let me ask Ruth, to make any comments you want to make. The process of AIDS case surveillance has been an evolutionary one. We did start out with gay men. It began before there was a laboratory test to diagnose HIV infection. And, for historical reasons there are some imperfections in the ways AIDS case surveillance came about. If we were creating it, de novo, given what we know today it probably would have some things differently in it. It's purpose is an epidemiological tool. To track the course of the epidemic, and it has proved, despite its flaws, and we recognize its flaws, we regognize there are people who die without a diagnosis... We are doing a study in New York City morgue, to find out how many people are dying with AIDS or HIV infection that are unrecognized. We can tell by looking at some of the graphs that Ruth and her collegues have put out that there are increases in some diseases,pneumonia, for example, that aren't recognized as AIDS that undoubtedly result from HIV infection. We want our AIDS case surveillance to caputure everybody with HIV infection but its utility as an epidemiological tool is based primarily on its capturing the most severe manifestations of HIV infection, but to be maximally useful as an epidemiological tool, it should include everybody.

US: Can I just ask you something? When you say "most severe", what do you mean by that?

GN: Ruth, do you want to comment, or Peter, do you want to comment on that?

RB: I will. But,I'd like to back up a minute, though. What I see is that HIV infection is occuring among the poor, they are most often women of color, they are the care providers, they're either taking care of children or taking care of someone else in the family and they often have no access to primary care and that I think HIV infected women need care and that goes beyond whateever we call severe or less severe or less severe than that.AIDS is the leading cause of death for Black women in New Jersey and New York State and it has been for four years. AIDS is coming up as a leading cause of death, this is in young adult women across the U.S. -- its going to be one of the top five. And I have, I think many of us have tried to work to show that the impact on women is here , we're not missing it,and we've got to attack it and I agree with you about that. To talk about the AIDS case surveillance, frankly, first of all I don't restrict myself to that data base. I'll use any data I can get ahold of, and looking at different causes of mortality, I'm pulling on vital statatiscs which is not confined to AIDS surveillance, its HIV infection or AIDS. We've also looked at other causes of death which are increasing in women. This is what Gary is talking about, including pneumonia*, including sepsis, including unknown causes of death in areas where there is a high incidence of HIV infection. Now it may not be on the death certificate but we think its related. And, I think its important that we really look at this. Your not really so far apart from us in where we want to go. In terms of the AIDS SURVEILLANCE DEFINITION, it was designed to track serious morbidity and mortality and how serious morbidity was defined was were people hospitalized, were they dying of the condition and at the early part it was the constellation of symptoms, we didn't even know it was HIV infection, what caused it. But we were trying to estimate two basic things: one was the number of people severly affected-- how do you define severe? Hospitalizations, life threatening --everyone would probably come up with some thing like that -- but the other was to track the epidemic -- where was it going -- was it going up in the heterosexual population? It is plateauing in homosexual men? By the way,it is not plateauing in homosexual men in this country.

*Chris Norwood wrote an article about this in NEJM, 3(?) yrs ago.

US: Can I ask...why you haven't answered all of the research....there have been articles in the newspapers, saying it is plateauing — it says the rate

MW(continued): is decreasing.

RB: There's a trend towards a plateau in the major metropolitan areas, but across the country there is not.

US: But, that information appears nowhere. I have not seen anyone from the CDC being interviewed in any one of those articles saying, "excuse me, this is incorrect". I have not seen that. I've seen plenty of articles but I have not seen one person from here respond to that. I just want to lay that out.

RB: Reporters want to have to report that as well.

US: But if you read it....I do certain kinds of work that has to do with something toally different. But if I read a newspaper article which incorreccly represents that stuff, I call up. And as the primary government agency that's responsible for tracking this epidemic, if you know that and a reporter in the NY Times puts out an article saying that its plateauing, I would assume that someone here does PR...I didn't mean to get off track, I just want to say that is something...

RB: We try. I just called a newspaper reporter this morning to tall him there were three errors in an article he had just written about women. So we try. We don't get it all. You're right. I don't think its coming out that strongly. We also ... I mean we try along that and we could try harder.

Let's see... when you change the case definition, when we changed it in '87, we did a much better job of capturing women. Not perfect, not great, but we changed it. Proportionately, a lot more women, IV drug users, people of color came in...and we were very glad about that. On the other hand, it did decrease our ability to track the trends and it did decrease our ability to do projections. And you've got to know that there is an interplay there with science. That if we suddenly jolt that trend, people.....For example, whether or not the large proportion of IV drug users, were also there before, we don't know. I think we needed to do it and we're glad we did it and we'll do it again if we think we're going to be including a large number of severely ill people . One thing about women dying without a diagnosis .. women, back in 1985, were twice as likely to die the same month as their diagnosis as men, and this to me points to that doctors weren't recognizing it at all and its points to the issue of early recognition by the clinicians and the surveillance system is dependent on the medical care system. If the medical care system isn't working,if people aren't being HIV tested and aren't being diagnosed, that's a problem. At Kings County, there was a report, that 40% more people would have met the AIDS case definition out of Kings County-- whether that's a problem with the case definition or a problem with the medical system--I mean there are a lot of issues here. There's also the issues of the diseases that are not being (inaudible) , that aren't in here, you mention the gynecological conditions...there's a lot more information coming in on them.

I want to deal...the Spectrum of Disease Study... it was set up to look at illnesses not captured by the AIDS case definition...vaginal thrush * should be reported through that..we are getting cases through that -- so I'm surprised at what I heard and I will look into whether there is a site that is not. The 7% issue ... we've just looked at our first cut and you are correct.. there are too few women, too few relative women- we're actually getting a lot of women but 7% was to us not what we want. And we have asked every site to concentrate and put as their high priority getting women, IV drug users and people of color, into this and if they cannot keep up with enrolling people, these are the ones they are to enroll first. And, we're carrying forward with that. **

*See Chip Rowan's statement on p. 19

** She was in response to our saying that Spectrum of Disease study was ending up being white men again and that we knew only 7% of the 4,000 people enrolled thus far (in one year) were women. (280 women out of 4,000 people)

RB(continued) One thing about not publishing, not capturing, the original diagnosis and not knowing later on, we have another study we just started where we are looking in several areas, we call it the National Death (unaudible) Study, people who are reported to us with AIDS, we are in these areas, going back and getting their death certificates and we'll find out why they died and I think that will help us....I'm going to let you address the cervical cancer issue

: Can I just ask you .. when you talked about changing the definition of AIDS, it decreased your ability to predict -- I don't understand why that is-could you talk about why that is and what affect that has on actually changing the defintion of AIDS

RB: When we try to forcast the epidemic and where it's going, say among IV drug users...(goes to beard and draws graph -- showing the level of IV drug users from 1981-1987 and then from 1987-1989. The second line begins about 30% above the end of the 1st line)...people are increasingly using the AIDS definition --- and we don't know that if this epidemic is really increasing among IV drug users or.....this line was beginning to tip up in 1987....so its taking time to figure out how real some of this increase was...that's all I mean. I mean we'll be able to do it- we can do it three years beyond, but when we start talking about changing the case definition we get a lot of screams from scientists, from all kinds of places, saying we can't track trends every time you do this because it threw everybody apart for a while. I think that this is the secondary reason, though. I think the primary one is to capture severe morbidity and mortality. So I mention this because I think its important but I do think its secondary.

: I just want to say something. In New York City 35-40% of people were hospitalized, who are severely ill enough to be hospitalized, do not fit the CDC definition of AIDS. If severe morbidity is the issue, the definition should already have been changed.

GN: Is that because they don't have the diagnostic capabilities.

US: No, I don't think we're talking about non-diagnostic ... I just want to get back to -- You Know, I look at the stuff that comes out of the CDC , If I were a health care practictioner -- we have to start out with that most doctors in this country know nothing about AIDS -- they don't -- most doctors don't know anything about AIDS -- so they trust what is written somewhere -- and most doctors in this country don't read journals— you can publish anything that you want to in a journal and you know they don't read it -- they find out about drugs from a detail salesman - we know how doctors operate -- unless they are researchers, they don't read journals-- and a lot of the researchers don't even have the time to keep up with all the journals unless they're well funded enough to have a research assistant who goes through it every month. I'm a researcher. I know what the story is. So the point is that the information that comes -- the CDC is looked to as the place that puts out this information. If every doctor in the U.S. got a letter from the CDC that said "these are the conditios -- we're changing the CDC definition and these are the conditions in women -- they would see it. It like the anti-rape hotline- somebody has to clue someone in that this exists. I've spoken to women who's doctors never ask them questions- about AIDS -- we have all kinds of prejudices going— they're less likely to be asked if they are white and middle class as if somehow that's going to spare them-- so do I know? Maybe there's a hidden epidemic aomong white middle class women who have AIDS -- just like the PHS never captures white drug usess -- they go to the private clinics and get detoxed-- this is why we always see women of color because they are forced to

US(condinued) come into contact with the public health system-- they go to the public clinics - so this is also why some gay men never get into your statistics because no one ever puts AIDS on their death certificate- we all know this - so for me, the reason for changing the definition-- As for the statistics -- there are such complicated statisticsl packages in the world, that I can't believe that adding another column is going to be that crucial -- I know they exist -- and I'm saying that the level of complicated statistics that can be done in the world, like predicting things on 5 cases, is not to be believed. That cannot be the issue here because what you are putting out in the HIV surveillance reports is basic statistics -- its numbers and percentages-- its nothing sophisticated. Projections are something else. I understand that but you know I don't care what the reason is at this point because not changing the definition is having more impact on the lives of people that worrying about whether your future projections are going to have an impact. If three years down the line you find out that that was not true, you can say that was not true. But right now the question of pushing people to test and pushing poeple to contact trace and all that kind of stuff when you are not giving people the information on which to take care of their own lives -- or the medical professional. We all go out and we speak to medical professionals and lots of them have not heard about 3/4's of the things we say if they have not already worked with HIV postive women. They haven't heard about it, they don't read the journals. It doesn't appear in your surveillance report, it doesn't appear in your classification system, it doesn't appear in the international calssification system. There's nothing in there. This is the issue right now It is that if the CDC changed the definition, every newspaper in the US would carry it.

GN: AGain, it gets back to the reason for changing that. There is a whole spectrum, all the way from reporting anyone with HIV infection, with or without symptoms, as you know, it can be based on CD4 cell counts, it could be based on any number of things, but if we did that we would be laughed out of the country for inflating the epidemic and the curve and simply trying to bring more money into AIDS research. There has to be a rational....

US: well we need money for AIDS research and, as for being laughed at, well..

GN: I know, what I'm saying is as scientists. I don't mind being laughed at but there has to be.....

RB: It was raised in '87, as to whether we were artificially inflating the epidemic; clearly we were not. But whether we include less severe or all symptoms of HIV infection is at issue. One of the things in the AIDS case definition, as well, is that most of these conditions are specific to HIV infection and many of the diseases that IV drug users are getting, people of color are getting, women are getting are not specific HIV but they are but they are increased and they are severe

Us: I'm sorry to interrupt you but it really raises my blood pressure. Why is herpes....I want to know then and maybe its something I don't understand scientifically but you have Herpes in as part of the definition-- Herpes Simplex Virus...why don't you have also cervical cancer -- I mean, they're both considered STD's-- as part of the spectrum of STD's -- I'm really not sure why -- I know that Herpes can get worse in combination with HIV -- I mean several of the disease that are listed in the CDC definition right now have caveats on them --Herpes Simplex with an ulcer that lasts for more than oen month, diahhrea that last for more than one month-- there has got to be a way to say that about women-- it is scientifically

US(continued): unacceptable that you can make those caveats for a particular group of people and not for another group of people.

RB: I think we need to look at it but I also think there's an issue of gynecological infections but there's an issue of other bacterial infections for women and IV drug users that are probably playing a larger role in morbidity. I think that this still needs to be dealt with and I still want you (meaning Bert Petersen) to respond.

BP: When we deal with the gynecologic concerns that have been raised, there are complications because we are talking about conditions that are very common, very common in all women. There are over 1 million cases of PID; most Americans, some (inaudible) have a prior infection with human papilloma virus. If you look at women, there are still a very substantial percentage of candida vulvar vaginitis, some (inaudible) cervical neoplasies. That adds an additional difficulty when we're talking about HIV infection in trying to determine the etiologic relationship between the infection and these other conditions because so many women who are not HIV infected have them. That raises a concern because if we talk about case definition because if there is a woman who is infected (HIV) today and has canida ~~vaginaixxx~~ vulvar vaginitis today, and yet would we want to say that she has AIDS?

US: Well would you say if she was treated as ...well, I'll just give you a case that's real -- that she's been treated for this over and over and over and over again and it doesn't go away and after a couple of months she starts showing lesions, etc., don't you think that there's a way that people can tell how common disorders differentiate when someone, when something else is at play. We have been told over and over again, that "all women get these things", that's not a good enough answer. Of course, you don't want to raise concern but it seems to me so contradictory. On the one hand, you are running out to "routine test" every woman which to me seems like (more) raising concern" that is beyond belief. So every women should be concerned so much that even if nothing is happening she should run to get tested, especially if she is going to have a kid. But on the other hand, you are telling us that actual infections that are in women that are occuring, they're getting treatment, its not going away, they're getting worse and worse and worse, we don't want to get people too nervous. What's the story? You want to get people nervous enough so that you can manditorily test all of them or "routinely" test all of them but you don't want to get them nervous enough so that they can look at their bodies or a doctor can look at their body and can say this is not responding. If all women get these disease then we know what "normal" is. We know how they all ordinarily get them. We also know what looks different. You don't have to be a genius to understand that. I don't get it. It's a way of dismissing things. It's just like saying we don't have to take care of this because its too prevelant. The difference between a woman getting vaginal thrush without HIV and a woman getting vaginal thrush with HIV is like night and day.

MG: I'm not sure I understand that. I see lots of patients . I work in an STD clinic. and probably the most common thing I see is vaginal candidiasis and its very difficult. Sometimes its mild, sometimes its very severe and very problemmatic. And, I think its just as problemmatic for the woman who has -- I don't think there's a difference of night and day-- its a problem for women, so to say there's, it's like night and day for HIV infected women . . . . .

BP: I take care of lots of women with refractory candida vaginitis

MG: That's one of the biggest problems I see -- women who don't respond to treatment and they're HIV negative

US: We know that there is a relation between immune suppression -- whereever that comes from -- we know that immunesuppression does fuel the growth of yeast - and I have an article "Autoimmunity as a Factor in Recurrent Vaginal Candidiasis" in Lancet and there are many articles on women who have immune dysfunction... I want to say one other thing so that we just set--- you just said and "some of them don't have HIV" (this was said to MG) -- the fact is that not every man who has AIDS has herpes -- some people get some symptoms and some people get others -- we all know that HIV disease and AIDS, there is no set pattern of symptoms- that is the problem that we are running into here. One, it gets dismissed because all women have it; and two, because some women who have a severe case are HIV+ and others aren't. Some men who have AIDS have severe Herpes and some men who don't have AIDS have severe Herpes and it doesn't seem to matter. The decision still boils down to that somehow in women that decision cannot be made. All women have to show the same set of symptoms or it can't be on that list of symptoms, but the list of symptoms,itself, is not something all people have to get. You don't require that every single person with HIV get every one of the symptoms. Otherwise we wouldn't need a list of symptoms; we would have one and we'd be sure that everyone got it and that would be AIDS but we have a list because its a syndrome. Right. We don't say that HIV negative people can't have these things, so its really....

RB: But, that is indeed often the case. There are not so many cases where healthy people get PCP. Some of the diseases aren't that prevelant.

BP: I think that's the problem because we are talking about common conditions.---severe PID, refractory vaginitis -- now about cervical neoplasias -- there are 21 reports all of which find a positive association between HIV and cervical neoplasias and although they are common in the general population we have some reason to believe they are more common in HIV infected women because of the singlular mode of transmission, we might expect HPV, genital HPV infection. What we don't know is the etiologic relationship between the two complaints. Is an HIV+ woman more likely to get it because she is HIV+ or more likely because of the sexually transmitted infection. So I think there is now substantial evidence to suggest there is an association between them and HIV-what we don't know is the natural history--the etiologic relationship, the influence of HIV on getting CIN, on cervical neoplasias and progression to cancer. There are one or two reports that suggest that it might be the likely cause of more rapid progression but from a scientific standpoint the jury is still out. The consistent evidence would suggest that there is a positive association; same thing I would suspect possibly with PID, if we're saying that women are more likely to have HIV because its an STD,PID is caused by STD, so we're talking about a lot of conditions that HIV negative women have but HIV+ women may bemore likely to get because of the commong mode of exposure. What we don't know at this point is the relationship between these two biologically, whether having HIV infection increases the liklihood or sewerity of neoplasias but we do know enough get the information aut to say that HIV+ women need to be followed for this condition, to keep in mind that they are at risk for this

US: So are you printing those recommendations?

BP: Well, we co-authored this metaanalysis (that means they combined the data from the 22 studies) and we're working on other documents so I think the clinical care are quite...we're recognizing it and addressing it but again, the case definition is problemmatic because so many women have cervical neoplasias and some have rapidly progressing cervical lesions that appear-- there are certain types that are more likley to progress rapidly and we really don't know if HIV+ women have these types-- so its difficult -- its really impossible on the basis of the data we have now to say that HIV infected women are more likely to have more rapid progression There are reasons to entertain that, theoretical reasons, immunosuppression -- we know that someone who is immunosuppressed is more likely to in normal pregnancy , because of changes that occur, HPV, a single lesion can have a much more severe clinical course, rapid progression in pregnancy, and you might expect that that might happen in an immunocompromised woman, On the other happen, it certainly can happen in the absence of immunocompromise for any reason, raise some issues particularly issues along natural history. We don't understand that. We do understand enough to be getting ready to make some recommendations but its separate from the case definition because of the other problemmatic issues we've raised.

US: I don't see why its so problemmatic . Part of the surveillance defintion is with laboratory evidence of HIV and without laboratory evidence of HIV -- so laboratory evidence of HIV — I don't think we can afford to wait for years for you to do the studies of causal relationships. Nobody waited for years to do those studies for gay men; nobody did it for children. They sat down people who worked with children and they said "what's going on"?. They didn't review the literature. If you sat down doctors who see lots of HIV positive women they will tell you what those women are getting and you can change the definition. If you need to prove how quickly, how rapidly, take your time and do it but right now it needs to be included. Nobody else had to wait. This is very very typical — white men do not have to wait to be included, everyone else needs proof, beyond a shadow of a dobut. I understand that people are going to yell at you for changing the definition. You know I think that if you are in a public position you have to have a thick skin. If you think its right and you think you can save people's lives, then that's what your job is and you have to be able to argue with people about that. If you can put out a definition and you can say yourself, for e.g. in the pediatric definition, we got together these people we sat them down around a table and they said this is what they are seeing, why can't you do that for women? Why only for women do you need total causal proof, why can't it include conditions that would be there otherwise except now there's HIV. Those conditions become life threatening with HIV; they are life threatening OI's

?: Vaginal candidiasis?

US: Itcould be, we don't know, but it could be leading to something that is — but I can tell you what would be -- PID is, cervical cancer is-- the point is that we don't need to require more proof of one group than of another -- you have a history of the way that you've created the definition and that history doesn't have to change and suddenly adhere to more scientific principles because women are involved, or iv drug users are involved.

RB: It didn't in '87.

US: You might say you need laboratory evidence of HIV -- so do it that way;

MG: Do you think the case definition ought to include everyone who's symptommatic?

US: Maybe, as long as you change what's a symptom. When I read, "HIV asymptommatic" I read "most women." Because symptommatic means a symptom you've got written there and those symptoms are not written there anywhere.

RB: Why would you want it changed? I was sitting here thinking about it: 1) as an educational tool: which could be addressed in a number of ways including the case definition, but that's one. 2) another reason I'm hearing is disability...

US: No,you can say disability. I know that those groups — like HHS has an independent responsibility to determine disabilitv-- the problem there is that they look to you for whatever you say --legally that's not your responsibility, its HHS's responsibility -- its your leadership role- the major point I want to raise is the educational thing and the other is the scope of this epidemic. We cannot get people to take seriously the epidemic in women unless they appear in your table; we cannot get doctors to seriously care unless they see infections that they are seeing and by the time they are seeing a woman with PCP she is ready to die and we know that there are things they could be seeing before them. And it even extends to the ACTG's..do you know that there has not been one— there's only one clinical trial of all the trials that NIAID has done in the ACTG's that ever did a pelvic examination- one, even though they only also have 7% women. They can't even go back to their clinical information; do you know it is not part of the NIAID contract to require people on research sites to have a gynecologist on their staff? That they have been looking for male markers in every woman who's ever been in a clinical trial and that goes back to the CDC definition. Lots of drug trials say "CDC defined AIDS". But more than them saying that ,it means that when they set up a research team, it means that they will not put a gynecologist on that team. They could be giving a woman a drug and it could be making her gynecological problems worse and they wouldn't know. Because no where is there anything published that suggests that they should be doing that. So it has multiple repurcussions.

RB: I think there are other ways to do that such as guidelines for the care of women.

BP: Like in the area of PID being life-threatening-- that's another area we are addressing now-- we are concerned -- partly with the education mission in mind--=if you take very common conditions and you say that any HIV+ woman who has them has AIDS, that has educational implications as well, some of which are not in the woman's best interests.

US: Such as?

RB: It means you are late in the course of your illness, even though they may have a CD4 count of 800.

GN: What is the natural history of cervical neoplasias - its usually very slowly progressing.

BP: Yeah, and depending on the DNA subtype much of it will not progress, regardless of how it is managed.There are specific subtypes that can progress some rather aggressively in non-HIV+ women for any number of reasons.

(an inaudible discussion about specific of types for a few seconds)

GN: Incident .lly, one of the world's leading experts on HPV, Bill Reeves, is here at CDC, and has a strong interest in this and is working In iare --what is the status of that study? (No response). Well, unless I'm wrong is a study to look at this. Again, this gets back to the issue of the logic of putting it into a case definition. If a person's life expectancy from HPV is not significanlty altered with or without HIV infection, what is the rationale for including it...

US: Well, KS is in there, come on..

GN: Well, as I've said before..

RB: Well, we've been thinking we should take KS out ...

GN: That's what I meant when I said earlier that if we were redoing it now.. based on what we know..I'm not sure KS or some others-- they are not life-threatening and they might not have been in there--

US: Well, I don't know. I have two friends who just died with virulent KS-- so you can talk about putting it in and taking it out --* but, all I want to say is I understand the need to talk technically and scientifically, but I still have not heard a good reason. You can say to me -- you know, I could give you reasons why someone wouldn't want an AIDS diagnosis-- because its stigmatizing. You know that the reason you are not getting some people in your count is, for e.g., if a woman comes into a clinic and she is already on disability and they diagnose her with AIDS, you're not going to find out about it because no one wants her name on your records, if she doesn't need it. This is the way people take care of themselves-- I'm giving you real life examples....**

* RB: We're not taking it out.

** An article in the NYT described gay men using private doctors during the same thing - not attaching on a diagnosis - some M.D's doing as for 80% of their patients

MG: But I don't understand how including vaginal candidiasis in the case definition will help that -- how will it save women -- I guess.

US: LEt me put something forward -- a different line -- it seems to me that-- and I think you will agree-- that a lot of women -- if we go to the doctor at all, we go to a gynecologist. Now, gynecologists know nothing of these symptoms in HIV+ woman. The Journal of OBstectrics and Gynecology published very little on HIV infection and, for instance, CIN. The information is not out there. If you change the definition and you put in PID that's refractory, with caveats of how long you have it, now that would be really change things, if you did that with PID in a gynecologists office or a clinic, a family planning clinic. The same thing if you have HPV and then 6 months later the woman comes back for a Pap and gets a class III and they would say, wait a minute, what happened, why is she progressing so fast. That would raise the awareness of people women are seeing. I think we know that that's true that as women, who do we go to. Our whole lives are focused on our reproductive organs.I'm not saying that that's right. I'm saying that bugs me. However, this is the reality of our lives right now. And I would think that it would certainly change the kind of health care if women were alerted to "hey, why am I getting this"

MG: Well, I agree with that for pelvic inflammatory disease as a life-threatening thing, that's an important issue but vaginal candidiasis

US: OK

MG: I want to know -- how do you save women's lives

US: Its a pre condition for something else -- such as vaginal warts. I mean I've watched numerous ones of my friends die exactly from that, It started with vaginal candidiasis and then it progressed to vaginal warts and then later an abnormal pap smear onto cervical cancer and before I knew it she was gone-- so its like a prerequisite of the progression to AIDS and yet no one is listening. I don't understand why you don't get it. You know I really don't

RB: Well, one thing, when I look at the list of diseases that are in the definition, most of those reflect a low immune status, a low (inaudible) count, and that has not..

GN: Is there any difference in the disease progression such as it is with herpes?

US: Can someone tell me why you care about oral thrush in men, and vaginal thrush is not important

GN: It is more severe in HIV infected men, right?

US: Oral thrush? Well,you haven't studied vaginal thrush in HIV positive women, so I don't know how you can make that statment, come on. The one study that is out on vaginal thrush is

(inaudible cross talk between RB, GN, MG)

US: The one study that is out on vaginal thrush does say that a woman presented first vaginally and then orally (esophagally) and if they had known to maybe treat more aggressively, and this is just my sense, as a lay health worker, to treat more aggressively. The clinic where I work and we see HIV+ women cause we're a free clinic, because AIDS clinics are not giving women gyn care in NYC, we are treating our HIV+ clients who have vaginal thrush and we're treating them with Monstatinand (inaudible) and this is over the course of a year and they have not gone on to have an episode of oral or esophageal candidiasis. Now this is because we're activists, and we're activist. lay health workers and we're putting these things together If you all would change the definition and put out standards of care then that would be different. Other people might treat aggressively. We could save a lot of women a lot of trouble-we could stem it vaginally.

MG: You mean that if they don't have an HIV definition, they are not treated. Every woman who comes to the clinic with vaginal candidiasis should be treated. I've just spent time testifying at the FDA hoping that they will change the over the counter preparations so they can get it and they've just approved that as of February. This February apparantly they'll come on the market but that's an issue that women don't get treated because they don't have the money for the therapy, they don't have money in the county to pay for it, so that's a big terrible issue which we've lobbied drug companies for trying to get them. But that's an issue of the clinics. But I don't know of a clinic that sends women away and says you don't have to be treated, you don't need to be treated for vaginal candidiasis.

US:It's not...I don't think its that women are being sent away and not treated but its when we would see someone who comes in and we don't know her HIV status and

MG: Right, right

US: and we're treating her for two and three months and we say you've got to change your diet and stop drinking alcohol and she's still having it. Now, if we were not activists and thinking -- I start to think -- now, this woman might be HIV+ --this thought crosses my mind--it crosses my mind because I've had the opportunity to do this research and think these things and work with activists. If you guys would publish this information, other people would begin to think like me and think "wait a minute, maybe something else is happening"

US: I understand this controversy about vaginal candidiasis...we've raised several conditions ..which of any of them do you see as being possibly added to the case definition? Which?

RB: I would say there is another issue here..the educational issue ..we're currently revising the classification system....I think that's an educational tool....

US: Which of any of these are candidates for you to be addeded.... we need to know this....you haven't answered that question....

RB: What are candidates? I think what we have right now..we'll be looking at the spectrum of disease data....we're talking about serious bacterial infections that we will be looking at, ok, in that project, that would include PID, sepsis, and a host of others. It's by far not the only one- in fact, bacterial pneumonia and sepsis are the leading ones...those are the ones I think we're missing...and the issue of cervical cancer.

MG: And PID is just one of multibacterial infections and more difficult to treat

RB: There are about four cancers we are looking at right now and I think the data are not really in on any of them--cervical cancer....

US: You have to understand our frustration..you've just told us that it is true that you have had a new 4,000 person study, the Spectrum of Disease Study, that, somehow, low and behold, there are only 7% women,

RB: Well, this is not a 4,000 person study..this is a surveillance.. it is more..this is not that you enroll 4,000 and you quit...this is ongoing

US: I know its ongoing...but somehow, in the way the sites were chosen, don't ask me, I know its not taking place in Newark, N.J., I know its not taking place in San Juan, Peurto Rico, I know its not taking place where you would have 3,990 women and 10 men .

RB: We've got 4 sites in the South..there were more women reported from the South than from New York and New Jersey last year

US: Then how come you only have 7% in the study? You are saying to us that we are again going to have to wait while you, just like the ACTG, figure out how you are going to get women into your study.

GN: But you were saying earlier that you were setting standards(to RB)

US: Yeah, now, for the new people who are coming in but already you have gotten 4,000 people and only 7% of them are women. So, what is this going

US:(continued) to be? Another 55,000 person male aspirin study?

RB: No, I stopped at 4,000, and said we need to set new criteria.

US: As far as I'm concerned that's 4,000 too many

RB: Well you've got several hundred women in there (actually 280)

US: Oh, except the 7% and, aboviously from what you said, there are hardly any IV drug users and its very low on people of color, right? You have to increase those two numbers also.

RB: That is where we know the least, there's not such a low number, we know the least about those groups.

US: In those 4,000, what's the percentage of people of color?

RB: I don't know. I'll be happy to get you that information.

US: I would like to know that. All that I'm saying is we cannot keep waiting year after year after year while this kind of study gets done and at the end of 4,000 cases you have to stop becasue there's only 7% women. That's not acceptable when people are dying. And, when you are telling us that you can't change the surveillance definition until the data comes in and then you are telling us that there are only 7% women and now you have to wait untilyou get the money to get some more women, what you are basically saying is that nothing is going to happen. That's not acceptable.

RB: We didn't say anything about money (*our source at the CDC did).

US: But when the case definition got made, you got information from clinicians. You can get people who have been working with HIV+ women who will tell you that they see cervical cancer, that they see PID that is virulent in HIV+ women ...what's the purpose of your clinical observations if you are not going to incorporate them?

RB: I looked at all the death certificates for women in 1987, infections may have been missed...

US: Yes, we saw that study (with Chu). But, why are we waiting until they are dead? I know what you are doing. You're trying to get it done quickly by going to death certificates instead of having to run a study..

RB: No, we've also got these other studies going

US: But why aren't you just convening ....doing the same thing you did early on for every other group..you got a group of people together who are doing this work

GN: The early definition was based on epidemiological data

MG: Yes we asked clinicians

PD & BP: Yes, we went around the country looking for more cases -- surveillance data --opportunistic infections -- it wasn't clear that it was an epidemic at first-- an epidemic of Karposi's Sarcoma, an epidemic of pnemosistis pneumonia- so we looked for everything..what we found got included in the definition..

US: But you didn't go and do 9 zillion research studies

BP or PD: That's the kind of research we do here -- field studies -

US: What I'm saying is that the information from the larger studies -- the natural history studies — didn't start coming in until way past your original definition

GN: Well, there weren't a lot of studies. Peter's been here since the first month of the epidemic and knows more of the history than anybody and there were very small numbers when these case definitions were made and they were based on the occurence of disease which was uncharacteristic in a person of that age and didn't have an explained etiology and those were the characteristics --vaginal thrush is not one of those diseases that would have been included in that original casedefinition

PD: and neither was oral thrush

MG: no we didn't include--the analogy was the people who were immunosuppressed-- the diseases that they get, as you said, and the diseases they get are these very unusual opportunistic infections

US: But, worldwide the major opportunistic infection is TB, TB that lots of people get. Are you saving that initially that's what you looked for?

MG: We looked for infections, that's what we were saying, that we, that immunosuppression was the reason for the disease processes and that any disease that we thought came as a result of --the bottom line was immunosuppression and then...for example, cryptococcal meningitis we weren't sure about because that can occur in some areas of the country so we decided yes to include it, depending on, and then with herpes, there were severe cases of herpes that first presented in drug users, actually, presented with herpes in NY, that was one of the first things, in fact, that's how I found out about those because I was a herpes researcher at the time and acyclovir was just being tested we looked at, you know, the herpes in these patients was so severe it had eroded everything. It wasn't frequently recurring herpes, it was herpes that never went away and invaded tissue and actually killed people. So that was a severe invasive disease. And, then we had a lot of problems defining it later on, why we would include herpes but the first cases we saw were terribley severe, but now we don't see that, now we have acyclovir ,it prevents at least some of the very severe infections that peple died from before so herpes was included because that's what a number of patients presented with first. And, why wouldn't we include PID in that..well, we may eventually

US: More to the point, why wouldn't you include HPV and CIN? Clearly there are studies that exist—I'm looking at this huge paper right here --"HPV in Women, Methodologic Issues and Roles(?) in Immune Suppression"... It goes over all forms of immunosuppression from HIV to renal transplant and chemotherapy and what are the outcomes in terms of HPV and cervical cancer. Now if you made that decision to understand PCP along those guidelines, for instance, PCP was an example you gave, I don't know why you -- it occurs in other immuno suppressed populations,who are HIV-, why don't you make that same decision now. Why are you resistant to changing it? And, this will affect both men and women with anal and genital papilloma virus and cancers.

and I'm sure you know this since you do this research

BP: I think that once people are immunosuppressed you can expect---like in renal transplant ...(inaudible)...the problem is that there are a lot of HIV+ women who are not immunosuppressed that have these conditions and there are a lot who are not HIV+ who do have these conditions....and some of them (inaudible)...and we are getting anecdotal reports of people who are caring for HIV+women and some of them are saying (inaudible) and some of them are saying cervical cancer and some are saying pelvic inflammatory disease, but if you go to any institution in the county, in a department of Obstretrics and Gynecology,we're taking care of a lot of women with cervical cancer and a lot of women with PID and they are not HIV+. How they relate is the issue and those studies take some time. It's a problem. But we also talked about the importance of the information being correct. We strongly feel the need to be correct.

US: I don't get it. You have not convicnced me. All I keep hearing and I still hear the same thing, that because these things appear in women, and because they just get worse when women are immunosuppressed, they shouldn't be in the definition of AIDS. And, that you are going to scare a lot of"nice" women who get these infections anyway but I know that the "not nice women" are going to die. And, I totally understand why you want to understand the etiology of everything in AIDS and frankly, there's very little anyone knows about MAI, toxoplasmosis, even pneumocistis, which is now breaking through after treatment. There is no --hardly anything anyone knows about any of the diseases that are listed as opportunitic infections--there is very little research that has been done on any of those diseases and why they follow the course they do in HIV+ people, and why some of them appear later and why some of them appear earlier and why they kill some poeple but don't kill other people. Let's be real. We don't know anymore about the male opportunistic infections that are in there. But the criteria that you are setting for putting in indicator and opportunistic diseases is a double standard. You have not required that from other indicator diseases or opportunistic infections and its just for women that you are requiring it.

RB: The indicator diseases in men are typically seen in poeple with low immune functioning. Vaginal candidiasis is sometimes seen in women without immune dysfunction. That maybe getting into the issue of how chronic, how severe,

US: Well, listen you have a classification system in which a doctor says "due to HIV or associated with HIV", I mean you are allowing a doctor to make a causal distinction in an International Classification System and you think nothing of it but allowing the same clinician to make

GN: It's like cold sores. We all have cold sores. But if I have a cold sore and I have a positive HIV test, I just seroconverted last month, that doesn't mean I have AIDS. Because everybody gets gold sores. Now, if it becomes worse and it becomes massive, whatever, like what herpes is, then it becomes an indicator disease but when I have a high CD4 cell count my herpes is going to go away just like it does in anybody else. So, to take something that's common and doesn't have an atypical course and add it to a disease definition doesn't hang together.

US: But it has an atypical course in immunosuppresed women

MG: Yes, but all HIV+ women are not immunosuppressed. And, so if we say, a woman is first infected with HIV and has vaginal candidiasis, their

MG(continued) course is going to be quite typical. I always believe that women should be treated for vaginal candidiasis. I don't think that its something that shouldn't be treated and I think it should be aggressively treated in all women so I don't think that adding it to the case definition will insure that women will be treated aggressively--I don't see that as happening. What I see is that --I believe that -- the candidiasis when the women become immunosuppressed, I'm sure the candidiasis is much worse, I'm sure it is, I'm sure all diseases are worse, PID, everything, but it depends on the level of immunosuppression

US: Well, is there any way that you can put that into a definition? What are you talking about? Are you talking about a T cell count below something-plus vaginal candidiasis equals...

MG: Yeah, if someone has HIV infection and has a normal immune system as we can measure it which is quite grossly and they might have quite a normal course and then I may see women who do not have HIV infection and have terrible problems with it retreating and refractory in therapy so this is a problem. In other words, I couldn't distinguish those on the basis of their symptoms but I think that both of them need to be treated and that both need to be treated aggressively and try to find whatever you can to treat them. But I guess I just don't think that to putting this on the --we don't, I guess, have the same sort of understanding of what will happen when these things are included, in the case definition, that this would help, that women would be treated better, that they would live longer, I just don't follow that reasoning.

US: Well, I don't follow that reasoning either, that's why I said that for me the major issue--I mean I do think that a lot of women who have those kinds of things that are immunosuppressed will be picked up who haven't been picked up before-I don't think there's any doubt about it - just like people were picked up when people put in presumptive diagnosis or wasting syndrome--I mean I think the reason that those people get picked up is because MD's know to look for certain things that they would not have looked for before--I think that specifically in terms of the case surveillance definition, I think that there's got to be a way of putting those OI's and indicator diseases in there that rests on the same trust you put in doctors when they have to say whether something is "with an AIDS-like disease" or "due to an AIDS-like" disease. You trust them there but somehow, again, when we get to women no one is willing to trust that clinical decision. Somehow in that situation we need extreme research. Some how we can't come up with a way to phrase it that would be acceptable. To me that's not acceptable. I can't believe its impossible to do. Medicine is not an exact science and yet we've learned to live with it, in its inexactness, for men, but we can't figure out how to do it under this circumstance and I do think it makes a difference. I think that in reporting AIDS cases for surveillance purposes, the reason there's a huge undercount, is that a lot of people don't want to make that diagnosis and we know that they definitely avoid making it

RB: who avoids making it? The patient or the doctor?

US: the doctor and I'm saying that in the majority of the cases where that is happening we will not have to worry about people suddenly rushing to put cases of vaginal thrush down as an AIDS diagnosis. Most doctors dismiss almost every complaint women have--they just do -- you're fatigued-every woman gets that-we're still living in "hysteriaville" in terms of the image of women by most doctors. So I don't think that by putting any of

US(continued) that stuff in, that you are suddenly get a rash of cases that are not AIDS. I think that what you are going to be doing is to be giving people who work with HIV+ women who are showing severe morbidity but that is how they are showing it before they get sepsis and die the next day. By the time that you get sepsis and you die, you die. To put that in so that we catch more women when they are close to death as opposed to putting in something that would require judgment but might alert somebody and the nation at large to the existence of these things seems to me to be irresponsible.

RB: When you talk about getting into less severe diseases and I think there would be women recognized early....

US: What's a less severe disease -- pelvic inflammatory disease resulting in a hysterectomy? Pneumocistis -- people live for years -- I'm not sure what you mean by less severe, certainly cervical carcinoma is not less severe, than what?

MG: she was talking about vaginal candidiasis

US: Everybody goes back to that because in a way, you think it lets you off the hook and you don't have to talk about the other things --I can't tell you how many women I know in NYC who have hysterectomies because they are HIV+ and they had PID and they don't know what the cause of it is, they say its not gonorrhea, its not chlamydia, they say could it be tuberculosis, what is it, but eventually "snip, snip". OK, now the woman has a hysterectomy, now what's going on? They are not alerting people earlier on to think that this PID maybe has to be treated differently, instead of going "oh, she's HIV+" and if I read another chart that says "HIV+, asymptommatic, refractory PID"and know the client is in the hospital, there's something wrong. And, that problem comes from here. If that woman is in the hospital, HIV+, with an IV in her arm and they are talking about well what should we do, well how come nobody thought earlier. We're not coming up with treatments, we're not coming up with prophylaxis. Another reason for us to do this is to begin to think prophylactically. This is to really push forward a prophylactic agenda on HPV, for instance.

RB: But, I'd rather find out all women whether they're "asymptommatic" or "symptomatic" and moving the case definition up to the person with PID who is already in serious trouble, doesn't accomplish that either. When you get into vaginal candidiasis and say this is a sign that there's sepsis, this is pushing it back earlier and I think that's exactly what you want to do but I don't think the case definitionis the only way to accomplish this.I think it is a spectrum of disease and we have to acknowledge that.

US: I think its great that its a spectrum of disease -- I would like women to be treated the same way as men. Men are in that case definition and women are not as far as I'm concerned and

RB: IV drug users

US: And iv drug users are not

RB: its not all a men-woman issue

US: I know its not all a men-women issue. I do know that women have a specific set of organs that do not appear anywhere in that case definition and

US(continued) that somehow everytime that gets raised, issues of seientific validity come up, issues of needing more evidence come up, issues of not fucking with the definition come up --we'll do anything, we'll give them more care, we'll give them this, we'll give them that, but its the one thing that's untouchable. If this is a spectrum of disease, its a spectrum of disease for men too

RB: It's been changed. It's been changed in '85, its been changed in '87

US: It hasn't been changed since 1987. Is it about to be changed?

MG: We didn't say its unchangeable.

US: Are you open to changing it along these lines at all?

MG: Oh, yes, we're very open to changing it

US: Along these lines that we've put out? When can we expect that?

MG: Well, I don't know. It would depend on if there is evidence especially about bacterial infections

GN: It's a little like syphillis and gonorrhea in men. It occurs all the time and having syphillis and gonorrhea with an HIV test doesn't lead to a diagnosis of AIDS

US: It should.

GN: Why?

US: How do we know that when people are going blind and we're calling it CMV retinitis that its not actually an advanced stage of syphillis. The tests don't pick it up or what about dementia --

GN: If they got a positive VDRL they get penicillin and it can be syphillis retinitis

US: They're not getting— what we're finding from the research I've done and other people who are serious about this is that researching syphillis and HIV are finding that people who are HIV+can't rely on VDRL and RPR's to get correct information about whether or not they are positive for syphillis or not because of their immune suppression -- that was published in MMWR I believe

GN: I can't comment on that

RB: You can include syphillis and gonnorhea and vaginal candidiasis and people who ask you where is the scientific credibility of it

US: You can include it and give the caveats that make it scientifically credible

GN: What caveats?

US: whatever: "persisting for a month and it doesn't respond to treatment"..., "laboratory evidence of HIV",.....that's what your definition is based on right now, its no different for women..its just the ability to stretch the imagination to think that one could ~~xig~~ write that in a way that would be

US(continued)relevant to women and iv drug users. We're not asking you to imagine something, you know,....these are real things..we're not talking about a bang on the toe....

RB: well, I look at pneumonia because I think that's an important thing..

US: It is. It's listed here too. (in our list of OI's/Indicator diseases to be added)

RB: Pneumonia is also seen in IV drug users without HIV + and HIV+ who are treated for the pneumonia and do great. It's not a sign of advanced immune trouble and on the other hand I'm bothered that there are people who will die with it and who are immunosuppressed. We're caught in that bind. We were never caught in that with PCP

US: This is more complex now, life is complex

RB: It is more complex

US: You've got to recognize that

RB: And we are open to recongizing that

US: And what you are saying about pneumonia is encouraging. Just like that there are other things that we broght to you today and I can't believe other people aren't bringing to you. I know you are seeing them in Grady. My clients come from Grady. I have a client right now, a woman, 9 T cells, severe PID, all kinds of other problems, gynecological problems and doesn't have an AIDS diagnosis

GN: What does Melanie Thompson say?

US: I haven't talked to Melanie, although I can respond to your issue about the Atlanta data base, I think (the Spectrum of Disease Study), I participated in the design of that and we were told that we should not try to try to capture data on vaginal candidiasis--because too many women get it

RB: Who told you that?

US: People working on the ad-hoc committtee to design that data base and when I asked could you pull that data up, about two months ago; I was told they could not, that it was not collected and entered, that they would have to hand go through the questions to look under "other infections", that it might appear under "other infections" in the Atlanta data. I worked on the committee that designed it, I mean

RB: Well, I have to look into that.

US: Well, I don't know how many women Melanie sees, but Sam Thompson told me that there were no studies that had ever been done to find out what's the difference between..is the candida that women with HIV are getting is candida albacans or something else -- (inaudible mumbling in agreement)

BP: But, if you go back to Grady, you have to have severe PID to get admitted but most of the women are not HIV+

US: Well, then they shouldn't get an AIDS diagnosis, but those who do

?: Why?

US: Why do you now have a system that says with or without evidence?

GN: That's like saying ..if you've got...the vast majority of PID admitted, some of it severe, some of it not so severe

US: People with PCP who have a had a kidney transplant or chemotherapy don't have an AIDS diagnosis; if they have HIV infection and they have PCP, they do

GN: Well, they are both immunosuppressed.

US: Whatever evidence you need of immunosuppression. I mean we're not saying pick out any disease anybody can get

MG: Well, that would be another issue then.

US: Well, you're also talking...I don't know who Melanie Thompson is but.. you can speak to doctors around the country,first and foremost among them I would say, Patricia Closer who would probably say, look I have seen 700 HIV infected women, I have watched so many of them die, I built this clinic up ...she is the person who came up with the study who said her clients were dying 15.5 weeks after diagnosis and she is the person who said to me tuboovarian abcesses is rampant and she believes its related to HIV, now if you believe Melanie Thompson, ok, but I happen to believe that Pat Kloser carries a lot of weight in this field of HIV in women. Pat Kloser has also said there's a connection between HIV,HPV, cervical cancer and rapid progression. This is what she's saying. Now I don't know who this woman is (Melanie Thompson) but maybe you should call her and check it out--Marge Cohen is saying it, Kathy Anastastas is saying it, women who see hundred of HIV+ women..these are scientists, these are doctors, why do you doubt them..

GN: Give us their names and where they are..

US: ok, I just want to say one more thing, what keeps coming up again and again--people will laugh, people will say that this is not scientifically valid...It seems to me that the history of science and women has been about kind of laughing and making light of

GN: (Pointing to MG) this is the lady who was quoted in time last week saying its ridiculous that NIH has stopped funding a study

US: Good for you

RB: (inaudible crosstalk about"laughing" issue)nobody's talking about laughing but you

US: He brought up laughing

GN: scientific credibility- MB: vaginal candidiasis

US: I think that scientific credibility and women's bodies is very questionable, in the first place. That science has ever treated women's bodies with respect is untrue. We have a history of abuse be it from sterilization, be it from death. We know these things so we have to say, fine, you are not going to say we are scientifically credible,because whenever you do research on women is it scientifically credible? Or do we have to deal with responses

US(continued) from people who don't want to take women's lives seriously and who don't think women's lives are important and worth saving. Now, I think you all have a lot of power and that you can use it in that way. You can say, this is what we're doing, this is why and you can create the caveats that are necessary and if you don't do it I personally sit and I hold people in this room responsible and I don't know what else I can do because we've tried to be as clear as we can...I'll give you the names of the doctors..and maybe you'll take it seriously .. they are the ones I've spoken to--I am not giving you this information from any place but their mouths..That's all we can say..I will send you a list of the rest of our demands with a listing of all of the diseases that we've come up with. I think its odd that you are trying to do a definition and you don't know the major doctors who are seeing women who are HIV positive across the country..I think that's peculiar

RB: The woman who's doing the spectrum of disease study knows them .. she's been calling them..it would be interesting to see if the women she's contacting are the same ones you are but all of us don't know everyone

GN: there are so many clinics all over the country

RB: she's been calling clinicians who treat large numbers of women

(talk about Judith Cohen being a Ph.D, not an M.D. and working with Connie Woofsey, M.D., Margaret Fischel)

US: Well, we expect a definition change

GN: Well, one thing I have to say is that ACT UP has its place, it has made a lot of changes and gotten a lot of attention and we will do all we can to make sure we are doing the best we can to make sure that everybody with HIV infection has eligibility for care and that they have a diagnosis that is legitimate based on the criteria that one needs to include in a CDC case definition

US: One more question. You said that you were open to changing the definition. Is there any kind of time line? Are we looking at a year or two, a month or two?

GN: I can't say...I don't know. Does anyone else what to answer that?

BP: Well its an ongoing process

RB: Its ongoing

BP: depending on the data

US: So we're still back to the same idea.. the idea of bringing together women clinicians who are seeing women..... and when you do you anticipate that there will be enough data

RB: I really can't say that its going to be a month or six months I will say that some of this data ought to be helpful...

US: You would save yourself an awful lot of trouble if you just got together all of these clinicians and just asked them what they were seeing .....(we get up to leave) I hold each of you personally responsible for the death of every woman with HIV I know, including myself.