PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS

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TWENTY-SEVENTH MEETING

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TUESDAY,

JUNE 21, 2005

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The Presidential Advisory Council meeting was held in Room 800, Hubert Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C., Louis Sullivan, M.D., and Anita Smith, Co-Chairpersons, presiding.

PRESENT:

LOUIS SULLIVAN, M.D., Co-Chairperson

ANITA SMITH, Co-Chairperson

ROSA M. BIAGGI, M.P.H., M.P.A.

JACQUELINE S. CLEMENTS

MILDRED FREEMAN

JOHN F. GALBRAITH

EDWARD C. GREEN, Ph.D.

CHERYL-ANNE HALL

PRESENT (Continued):

KAREN IVANTIC-DOUCETTE, M.S.N., FNP, ACRN

RASHIDA JOLLEY

FRANKLYN N. JUDSON, M.D.

ABNER MASON

SANDRA McDONALD

JOE McILHANEY, M.D.

HENRY McKINNELL, JR., Ph.D.

JOSE MONTERO, M.D., F.A.C.P.

BENY PRIMM, M.D.

DAVID REZNIK, D.D.S.

REVEREND EDWIN SANDERS

LISA MAI SHOEMAKER

M. MONICA SWEENEY, M.D., M.P.H.

RAM YOGEV, M.D.

PACHA STAFF PRESENT:

JOSEPH GROGAN, ESQ.

DANA CEASAR

C-O-N-T-E-N-T-S

C-O-N-T-E-N-T-S

P-R-O-C-E-E-D-I-N-G-S

(8:35 a.m.)

MS. SMITH: Good morning. We thank you for being here and being ready to work. I think that one of the things that we will be able to do today is have some discussion based on the good work of the different committees that have been convening between our last meeting and this meeting. We'll have some time later to have some discussion.

I've been privileged to attend the different committee meetings that have gone on since the last full Council meeting and really congratulate you all on the hard work that you've been doing and the good work. Interestingly, we talked a bit yesterday about the prevention outline that you all had. The Prevention Committee did exactly what was recommended by the full Council, which was to go and have a discussion about what they would recommend if we were to try to eradicate HIV from the population, or get to zero new infections. So that outline that you've been looking at is a result of what you tasked them to do.

We'll have a chance to have some discussion about that and some other motions and an outline from the International Committee that will be introduced a bit later.

Today we are trying to keep right on schedule. The challenge is we have a lot of members that are leaving, and so we're trying to accomplish as much business as possible with as many of us here as possible. So we will be changing the schedule a little bit in that we won't be breaking up into committees, but we will have a working lunch here together so we can have ongoing discussion and accomplish, again, as much as possible with as many members here as possible. If there needs to be some sidebar conversations with different committees who need to discuss a few things together, that can happen as well.

I think that we will introduce the motions at the time when we have that working conversation just before lunch, after our session with Joe O'Neill and Carol Thompson.

With that, I'll ask Joe if he has -- no?

No announcements? Then we'll turn the microphone over to Dr. Sweeney for the next presentation on the Prevention Committee.

DR. SWEENEY: Good morning, everyone, and it's good to see all of you that were able to make it.

I had the pleasure this morning of riding in with our speaker who is going to talk to us, Edward Richards, III, J.D., M.P.H. I've been forbidden to read his bio. It is in our books. It is impressive. Please read it, but not now. He got here to us this morning from Louisiana, and I want you to know he has worked in HIV -- no, he worked in STDs before HIV, and he has a different perspective, and you're going to really be enlightened, and it's a pleasure to welcome him this morning to be our first speaker.

MR. RICHARDS: Good morning.

I actually worked in STDs when we called it VD, to tell you how long ago that was. I feel like the ancient mariner. I'm going to grab you by the lapels and tell you a story that I hope will captivate you, but it's a story very different from your experience.

I'll talk about AIDS law, but more importantly the history of public health and public health law in this country in the critical period in the '70s and '80s, when things shifted. All of this is seamless. I got into this even before I was a lawyer. I came out of the medical sciences. My wife is a physician, a specialist in public health, and her first job out of residency was running the City of Houston's VD control program in the mid-'70s. That's when VD was big business, 80,000 patients a year through her clinics. As I went through law school over the next couple of years, I became her lawyer because health departments seldom have good local counsel, went on to get interested in this and have kind of carved out a niche as a VD, then STD, then STI lawyer.

Last week, headlines from the Atlanta Journal Constitution from the prevention conference. Suddenly the number of folks with HIV went up 100,000 from the week before. We have a quote: "The HIV epidemic is not over in the United States like many people think it is." That's really the theme of my

talk today. I think it's beginning, not over. We made some critical mistakes early on, and there is still time to change those. If we don't change them, I think this headline, every year we'll see that number go up.

I want to put public health in historical context and explain the breakdown in support for public health in the 1970s. For some of you, you'll remember that. For some of you, this is going to be a history lesson. It's so discouraging when I teach my students and realize that what I think of current events might as well be the Punic Wars for them.

This breakdown led AIDS exceptionalism, and what I'm really talking about today is treating AIDS differently than other communicable diseases and why that doesn't make sense. Finally, I want to explain what we can do to change that, and in the narrow context of traditional epidemiology. I could talk a lot about a lot of other things, but you only gave me 40 minutes.

Traditional public health law dealt with external threats to the individual, communicable

diseases, environmental hazards. In the last 30 years, public health has wanted to redefine itself as everything that makes you feel good. That may be a nice thing, and chronic diseases is certainly an issue, but the core of public health is external threats, not internal things you do through self-awareness and self-interest.

Many of the public health concerns put individuals or businesses in conflict with society. A key thing to understand about public health is that if education and self-enlightenment would cause people to do what's right, we wouldn't need public health. We wouldn't need public health laws. We've gotten into this notion in the last two or three decades that education is all there is in public health, at least in the context of diseases like AIDS. That isn't the case, and that's what we need to talk about.

Public health law is old. Leviticus is full of public health admonitions. Things like, "don't eat shellfish" makes a lot of sense if you live in the desert and don't have a refrigerator. The Romans brought us waterworks, sewers. They didn't

understand germs, but they did sort of understand that you didn't want to drink the same water that your toilet ran into. Venice brought us the 40-day cooling off period for ships that came into the harbor, which we now call quarantine. Blackstone was the great chronicler of the English and then Anglo-American common law, and quarantine and public health is part of that body of laws, that death was the penalty for breaking quarantine, because in those days breaking quarantine could threaten the nation.

We lose track in the modern world that the U.S. colonies were all around coastal areas, around rivers, because water was the major transport. That meant that you had cholera, yellow fever, malaria, you had smallpox and tuberculosis, especially in the urban areas. The average life expectancy as late as 1850 was 25 years. That's a very frightening number. In fact, if you read Colonial records and early records from the Constitutional period, communicable diseases dominated people's lives. The Constitutional Convention was almost disrupted by a yellow fever epidemic.

Colonial America used traditional public health measures, quarantines, areas of non-intercourse which are isolating different parts of the country, inspecting ships and sailors, what we call nuisance abatement, tanneries, noxious conditions. They had Draconian powers, and they used them. These are called the police powers. It didn't have anything to do with police departments. This was long before police departments were invented.

In essence, public health was one of the major functions of the early state. Powers were doled out between the states and the federal government in the Constitution. Public health powers were one of the key things they thought about. If you're a strict constructionist, this is one of the areas where you probably have the best evidence of what went on, because communicable diseases and the methods to control them were within the personal knowledge of everyone at that Constitutional Convention.

The federal government was given interstate commerce power, international trade and travel, war, and national security. The states were

left with powers not given to the federal government, and of these at that time, the most important were the police powers, all the public health except that related to foreign shipping and commerce. One of the first acts of Congress was establishing the Public Health Service and the quarantine stations to deal with foreign trade.

Now, these powers were so great because in that period of time, public health was seen as national security. There's a book called "Bring Out Your Dead," which is a description of the 1798 yellow fever epidemic in Philadelphia. That epidemic killed 10 percent of the population of Philadelphia in one summer and fall. The city was in chaos. The state was paralyzed. It really brings home the notion that in that period epidemic disease was seen as one of the most important security threats to the state. They weren't that concerned with the health of individuals. I mean, it was nice if people didn't die, but they were really concerned about the state.

If you look at the history of the Black Death in Europe, "Plagues and Peoples" by William H.

McNeil talks about how the Black Death broke the back of feudalism, changed the social order in Europe. So the courts and the Constitution have always seen public health powers as national security powers. In essence, public health is the state's component of national security.

If you study national security law, you'll be frightened how far those powers go. We'd forgotten about that nexus until the anthrax letters, that reminded us that there is a nexus between national security and public health even in today's world. Public health in sort of the grand period, what we call the sanitation movement from 1850 to 1970, dealt with improving drinking water, disposal of waste water, pure food, also pure drugs, housing codes, working conditions, and communicable disease control, vaccinations, disease investigation and control.

This included the classic public health interventions, mandatory reporting of cases by name, no anonymous testing. No one ever thought of anonymous testing prior to AIDS. We have reporting cases of physicians being disciplined for failure to

report that go back into the 1800s. In fact, we probably have more of them in the 1800s than we have now.

Disease investigation involved tracing contacts. This could be talking to everyone who ate the bad potato salad at the picnic to interviewing people about their personal sexual histories. We also did screening, tuberculosis screening. I can remember when I was a kid, and a few of you look like you're old enough to remember, when the truck would come around and we'd do our TB screening x-rays. We screened for syphilis for years. In fact, syphilis was brought under control for the first time in this country post-World War II. We screened folks who went into hospitals, we screened folks who wanted marriage licenses, and we came fairly close to eradicating syphilis, although the resurgence of sexually transmitted diseases is sort of making that goal a lot more difficult to contemplate than it was, say, in 1947.

We did interventions. We did contact notification, which was then turned into partner

notification, although somehow the notion of partner on your thousandth and first anonymous sexual contact seemed a little bit overblown. But it's the most important thing you do in public health. It lets you warn the person that they've been exposed to a disease. It lets you help them get treatment, testing, social services, and it's the best educational opportunity you ever get. We'll talk later about why it's particularly important for HIV.

We educated people. There is a very important component to public health of education. Education is not the only component, but it is a critical one. We offered treatment. We frankly coerced people into treatment. We don't like to talk about mandatory treatment. We just explain to people how we'll keep them in a dank cell for the duration of their tuberculosis unless they agree to be treated.

Sometimes the state doesn't want to have two deputies sitting on someone to give them their tuberculosis medicine, but we do a lot of things to encourage them. We do isolation and quarantine, when necessary. Tuberculosis has been most of the focus of

that in the last couple of decades, but we have other restrictions. Typhoid carriers still can't work in food handling. It's sort of a part of the large public health picture that mostly is below the horizon. My wife was a health director in some major cities for a while. I saw a lot of things there. I've worked with other health departments. There's a lot of things going on the public doesn't really pay any attention to.

During this period, the law followed the best public health practices. It's impossible to talk about public health law and public health separately. Law is the core of public health. The courts uniformly supported public health laws. There were some times when health departments used public health laws as a subterfuge for other activities. Laws were struck down that applied only to Chinese laundries. Laws were struck down that were using public health rationales to sort of have what we call non-tariff barriers to interstate trade; a whole line of cases on milk. State A says the milk can't be sold if it's more than 24 hours out of the cow. Well, maybe that's

good for State A, but it makes State B's milk impossible to sell in State A.

The Supreme Court pretty thoroughly said you can't use public health rules as trade restrictions. We still see that with the fight between us and Europe. They want to sell us stinky cheese, and we want to sell them hormone-laden beef. The WTO will weigh in later this summer.

Probably most importantly is public health departments had public support. People cared who their health director was when they were scared to death of dying of communicable diseases. The results were phenomenal. Life expectancy almost tripled. Tuberculosis and polio were under control. This is as of 1970. Food- and water-borne diseases are rare. Yellow fever, malaria and smallpox are eradicated in the U.S. Vaccinations and disease control are routine and not controversial.

For public health and support for public health departments, 1970 was probably the high water mark. What changed was, frankly, public health worked so well. Surgeon General William Stewart testified

before Congress in 1969, or at least is reported to -- I have yet to find the actual transcript -- that it was time to close the book on infectious disease. That was certainly the prevalent view in the medical community at that time. There was a huge debate in, I think, '70 and '71 about stopping smallpox vaccinations in this country because smallpox was eradicated in the U.S., it was 10 years before worldwide eradication, and we started to be more concerned about the risks. Most vaccines are harmless; that one is not.

Some people said if we do this, in 30 years no one will be immunized, and then what terrible things might happen? Well, it's 30 years later. We run scared of smallpox bioterrorism. But this was a point where people could talk about eradicating diseases. This was the high point of antibiotics, the magic bullet. People were convinced that communicable diseases were curable. My mother-in-law trained in medical school in the late '30s and early '40s, really before effective antibiotics were widely available. It's interesting to hear her talk about how medical

students were taught sanitation and hand-washing, because it was not just a threat to their patients, it was a threat to themselves.

Now you see it's fashionable to run around in surgical greens in and out of the hospital. Those were invented so we could make sure we knew what was sterile and what wasn't. We don't care about infections because they're easily treated, or so we thought until antibiotic resistance reared its head.

This is a quote from an article a man named Rosenau wrote. Some of you that are aficionados of public health know that Rosenau then went on to write the first preventive medicine public health textbook, Maxcy-Rosenau, "Public Health and Preventive Medicine." I think the last edition was in 1912. I think we're up to the 16th edition maybe. "Reasonable fear saves many lives and prevents much sickness. It's one of the greatest forces for good in preventive medicine, and at times it's the most useful instrument in the hands of the sanitaria." He was talking about in those days why a few typhoid cases were good for the public health department every year, because it

kept people's attention focused. He was quite a prophet.

Other things are going on in this period, Medicaid and the Great Society. These are wonderful programs, but they created money for indigent care, a lot of social services, which are very important, but these started being done by health departments, and health departments started becoming centers for personal medical services, not traditional public health services. Personal medical care displaced public health expertise. Look through your health departments at the state and local levels, and look at how few board-certified public health physicians there are in those departments. Most of the board-certified public health physicians I know can't find work in public health, it's so unfashionable now.

More importantly, medical values: autonomy, privacy, displaced public health values, protection of society. Vaccine liability became important in the '60s, and particularly the '70s. There was a major vaccine incident with the very first polio vaccines. Some from Cutter Labs didn't work

very well, and some people got polio. But in 1965, a restatement of the law of torts came out and invented this new concept of products liability, strict liability even if you couldn't have changed the outcome, even if you couldn't have known. This is what fueled drug and vaccine liability.

Another piece of the puzzle, the Stonewall riots, 1969. This focused public attention on the harassment by police of gay men and women. It was an important move forward in human rights and in gay rights, but it also showed politicians in big cities that the gay political groups were powerful, and their supporters were powerful. That was critical because it made public health actions -- well, I should say it made closing bathhouses, which also arose in the wake of Stonewall, politically impossible.

Now, keep our time frame in mind. We're sort of moving through the '70s. The pivotal event in most people's minds for public health, if they think of it at all in the 1970s, was swine flu. We're worried about avian flu pandemics this year. All of you worried about avian flu should go back and read

the HEW report on swine flu that was issued in 1978. I think it's referenced on my website. There's also a wonderful book called "The Epidemic That Never Was" that analyzed our thinking about swine flu. We were worried about a global flu pandemic, and that was a perfectly legitimate worry. I worry more about global flu pandemics than I do about bio-terrorism.

Vaccine was rushed into production. The vaccine manufacturers were nervous about this. They demanded indemnification, complete protection from liability from the federal government, and the federal government set up its first big vaccine compensation program, although it kind of did it by giving a blank check. There was a massive push to vaccinate the public, and unfortunately -- well, fortunately for the public, unfortunately for public health, there were no cases of swine flu. It even turned out you could blow it up people's noses and they didn't catch it. That was very embarrassing.

The epilogue is a critical part. Guillain-Barre syndrome surfaced. There's no lab test for Guillain-Barre, at least there wasn't then. I

don't think there is now. It is an amorphous set of neurologic symptoms, historically pretty rare but there's a whole lot of people with strange neurologic symptoms. At the time we thought we had Guillain-Barre secondary to the swine flu vaccine. We had a comp fund, which means lawyers had a real interest in getting patients to sympathetic docs. The docs were getting notes from the CDC that Guillain-Barre is a big problem, so you've got a patient with iffy symptoms who's had a vaccination, like two-thirds of the people in the country had, and Guillain-Barre makes sense.

Huge liability for the government. Got a case cited that discusses some of that. But ultimately, it turned out there wasn't any scientific support. There's a great piece of epidemiology done in '99 reevaluating the data. The problem was, combine massive immunization campaign done at the Presidential level because the world was going to end, and then no cases show up, and then people get sick from your vaccine. That hurt the credibility of public health terribly at the local level, the state

level and the federal level. It took years, I would argue maybe until 9/11, for some public health departments to start to recover their confidence.

Now, why does this matter? Because at the same time this is going on, the reports on hepatitis B in the bathhouses are coming in. Hepatitis B is not a nice disease. If AIDS hadn't come along and HIV, we'd be lamenting the enormous toll of the hepatitis B epidemic. But, hey, HIV killed everybody who had hepatitis B, so we don't think much about the hepatitis B epidemic. Almost everyone who was active in the bathhouses -- we're talking about hundreds of thousands of people -- became infected with hepatitis B. We did great epidemiology. The gay men cooperated with the epidemiologists. We did great studies that helped to develop hepatitis B vaccines, but nothing was done to close the bathhouses.

In fact, I've talked to folks that are in charge of large HIV and AIDS control programs who didn't even know this went on in the '70s. It's lost in the literature. I think one of the big reasons is health departments were utterly and completely

distracted by swine flu, and I think in the aftermath of swine flu they were even less likely to recommend unpopular actions, and the politicians who would have to sign off on those actions were even less likely to support those actions. So it's a confluence of hepatitis, the bathhouses and swine flu where I think we have to really start looking at this.

You have to remember that HIV was rare, small introduction. HIV is hard to catch, fortunately, because if we look at our gonorrhea and chlamydia numbers, we'd look like Africa if HIV was easy to catch. Bathhouses amplify epidemics of diseases. They amplified everything, giardia, syphilis. Syphilis was a better marker for being a gay man in 1980 than HIV, or in '81. You have a lot of contacts, a lot of different people, a lot of co-infection with other sexually transmitted diseases, a lot of IV drug users crossing over. These were the incubators for HIV between '76 and '80, before it was on our public health horizon.

If the bathhouses had been closed in the '70s, we might not be sitting here. We'd have HIV in

this country, but it would be an enormously smaller problem, because we never recovered from the initial seed, the initial 300,000 or 400,000 gay men and IV drug users who were infected during that period when we were figuring out what was going on, most of those infected through the bathhouses. There are some tremendously interesting mathematical models on this from a statistician at Rice. This was also the start of AIDS exceptionalism before we even knew we had AIDS. This was the point when public health, at least for AIDS, broke free of traditional disease control and was seen as a political issue, and the carnage has been terrible.

The first cases we called GRID, gay-related immunodeficiency disease. Then it was AIDS. We worked out the epidemiology pretty quickly because, gee, it was exactly the same as hepatitis B, which we understood from the bathhouses, and it was exactly the same people. All the concerns about privacy were really kind of silly because everybody's names were already on the hepatitis B list.

There were enormous initial fears, and

some of us remember those. They wanted to fire all the gay waiters and hairdressers. There were claims of housing discrimination, although those turned out to be fairly difficult to substantiate. But there was fear and prejudice against particularly gay men. Frankly, IV drug users have never had very good press, so that didn't change a whole lot. Civil libertarians thought the secret to this was to keep everything about AIDS confidential or anonymous. That was probably where we should have said no in public health. The bathhouses were still left open, even though we knew they were part of the epidemic and were still spreading the disease.

In New York they closed them in 1985 when so many people died that the resistance went down. Public health experts who pushed to close bathhouses were fired. Bathhouse owners, gay activists, and even some public health people who were probably fundamentally individual medical services people said, "No, no, we need to keep them open, they're good places to educate about safe sex." Some were never closed, and others have reopened. I believe all of

your major cities now have active bathhouses again. What have we learned?

HIV tests came around in 1985. This was the point where we could now detect the carrier state, which for a disease with a very slow latency, like HIV, is very critical. Some states just added this to their communicable disease list. I believe it was North or South Carolina reported HIV by administrative regulation. Colorado passed the first HIV reporting law, which I had the honor to work with the folks there in Colorado on. I think we have some folks in the audience who remember that period.

We got enormous grief from gay activists and so-called public health activists when we presented that to the legislature. They explained to the legislature how we had invented communicable disease reporting just to harass gay men. We were shocked to discover the legislature didn't know we'd been reporting 50 other diseases for the last 100 years.

None of the states that had high numbers of HIV required reporting. In fact, they didn't

require it until relatively recently in the epidemic, and one of them still doesn't. California still has coded reporting. Anonymous testing came around. This was probably the most troublesome part of the whole epidemic. Health departments have always had people who would register at the VD clinic as "Minnie Mouse." You went with the flow, you treated them, you didn't worry about it, but you sure didn't encourage them to do it. There's no real evidence that anonymous testing increases HIV testing, although there's certainly a lot of rhetoric to that effect.

But anonymous testing stops reporting and investigation cold. It stops epidemiology cold, and you're even left with a terrible problem that significant people never come back for their test results. So you're sitting there with a positive HIV test and nobody to go talk to. A very frustrating business.

The federal government actually kind of coerced states through funding requirements to offer anonymous testing because some states didn't want to do it. It's still offered in most states. My friends

in North Carolina say it's not offered there, but I'm not even sure that's true.

Reporting is the key to all epidemiology. But all the disease reporting in this country is local, flowing through the state and to the CDC. There are no national standards or laws for communicable disease reporting. HIV data is weak because of anonymous testing, lack of named reporting, and no contact investigation. This is the most important sort of scientific point I want to hammer today. All of our numbers on HIV in this country are based on mathematical models, not on hard epidemiologic data. I've worked with mathematical models a lot, and they predict what you want them to predict.

As I say, I was struck that over one week's time we came up with another 100,000 cases of HIV. We went from less than a million to 1,100,000. Those models will generate almost any number you want depending on how you deal with the assumptions you put into them. For the last 10 years, it's been fashionable to say prevention is working and education

is working, and to say we've reached an equilibrium. The new populations keep popping up because you get infected with HIV and you don't show up with AIDS for years later. We don't know where the disease is going. We don't know the actual number infected. Maybe it's lower. Maybe the models are wrong. But we don't know, and that, as an epidemiologist, should make you crazy.

Contact tracing is the way you find hidden cases. Many states don't do it because they see it as an invasion of privacy. It's also expensive. It also requires named reporting and no anonymous testing, but it doesn't have to be perfect. There's brilliant work by some folks, Hethcote and Yorke, on gonorrhea that really explains to us about how sexual contacts are this big web, and you start unwinding that web and you'll eventually get to most of the people you need to get to, even when people lie to you or won't talk to you. So for HIV it's particularly effective because once you're infected, you're always infected.

Contact tracing for 2 million cases of gonorrhea a year, when five minutes after you're

treated you can be reinfected, is hard to justify. Contact tracing for a disease where once you're on the list, you're on the list until we get your death certificate, is very cost effective.

It's natural. You've got the contacts, you warn people. People have said, well, this interferes with people's right to not know they have HIV. That's a crazy notion, and there are times when you can't keep it anonymous. If you're warning the monogamous, faithful wife, she's going to figure out where she got it. My wife was running the VD clinics, gunfire was not unknown in the parking lot. There were a lot of marital disputes and partner disputes because Partner A thought Partner B was faithful, and the VD clinic unfortunately disabused them of that notion.

But the point is the person who is being exposed has a right to know, particularly when it is a deadly disease. Remember that headline we saw at the beginning? Secret bisexual sex is really a major problem for poor women, particularly minority women. The most encouraging thing about contact tracing and partner notification for HIV is because it's hard to

catch, you often warn people before they're infected, and that's the best time for them to do something about it. It also allows you to get them social services. For poor women who have a husband or boyfriend who is exposing them, they may not be able to get away from him on their own. They need the state to help, and they are the people who are left out of HIV control when you don't do disease control.

A lot of talk about disease control costing too much, kind of the notion that if a disease spreads wide enough, we don't do anything about it. Well, if you're a public health department with no money, I'm sympathetic to this argument. The feds can't just say, "Do it." The feds are going to have to change funding priorities. But the human cost and the financial cost of HIV dwarfs any amount of money we'll spend on control, particularly because we don't know where this epidemic is going. Since we don't even know why the epidemic looks the way it does in Africa because epidemiology of HIV is not good anywhere, we should worry about this.

HIV needs to be part of routine medical

care. Every doc needs to think about HIV the way every doc used to have to think about syphilis. But you can't do that if you can't do routine testing the way you do for every other medical test. It delays diagnosis, it delays disease control, it hurts epidemiology, and I believe that until you mainstream a disease, it will never end discrimination. Read the history of cancer. Through the 1950s, cancer was a stigmatizing disease like HIV is, and it wasn't until bioethicists and others made that point that we had to talk about it, we had to be open, we had to treat it like other diseases, that cancer became mainstream.

If we're worried about privacy, HIPAA will take care of that. HIPAA has a lot of issues with it, but it certainly answers all the questions about privacy and medical records, and it's a federal uniform standard. Routine testing should be part of medical care and we should not have state laws that put special requirements. It should be no different than ordering a serum sodium or an x-ray.

Now, another point that's kind of been lost if you aren't an aficionado of public health law,

in 1980 I think there were about three people who had anything to do with academics interested in public health law. Frank Grad, who just got the career achievement from the Public Health Law Association, and who I kid was Louis Pasteur's lawyer, myself and one other person, and I was only interested in it because my wife ran a VD control program and she's asking me for advice.

In the '80s, as AIDS came along, every Constitutional lawyer, human rights lawyer, mental health deinstitutionalization lawyer, and you know what great things they did for our mental institutions, became retreaded as a public health lawyer. They weren't public health lawyers; they were AIDS lawyers. Public health law became AIDS law. Even the federal government funded AIDS activist groups as public health researchers. Not only did they screw up AIDS law, they attacked other public health laws, quarantine laws, isolation laws. There was this drumbeat in the academic literature, with a very small number of exceptions, that the courts shouldn't uphold traditional disease control laws,

that somehow the Supreme Court had changed its standards.

I'd usually flash a picture of Justice Rehnquist up and say you've got to be kidding. But they've been very successful. States have adopted emergency quarantine laws as part of their emergency public health laws that require such a high standard for imposing quarantine that I expect they're going to have a firestorm of litigation if they ever use them. They increased the restrictions on the state in emergencies. I'm not even sure they knew they were doing that.

Where do we go from here? End AIDS exceptionalism everywhere it is.

Federal government's role. Public health departments in most states only do what you pay them to do at the federal level. States don't support public health. I can tell you, in Louisiana, if the feds aren't paying for it, we don't do it. In fact, our problem is we get caught taking the federal money and not even doing what we're supposed to with it. That's not limited to my fair state.

Most of the things you need to do can be done through federal funding incentives without changing federal laws. We don't need federal public health laws, and that allows us to jump past that debate about whether the feds have police power. It will require changing state laws and rules.

I think federal funding ought to come with certain requirements. No more anonymous testing. If you do anonymous testing, you don't get federal AIDS money. Named reporting of all positive HIV tests, screen pregnant women, end all special requirements for HIV testing. It should not be different than any other medical test. Post-test counseling is nice, but it shouldn't stand in the way of testing. There are a lot of bad things, like cancer diagnosis, that have the same issues as HIV for post-test. We don't stop docs from doing your cancer diagnosis because they can't come up with post-test counseling, and pre-test counseling should just vanish because it's one more thing that tells people this is something special you should worry about.

Frankly, people don't trust the

government. When the government says you should think extra about this, people rationally say, "Hmmm, I probably don't want that." Now, the federal government has got to put their money where their values are. You have to supply the money, whether it's reallocating it from other AIDS program. That doesn't bother me because in public health, I'm more interested in preventing the spread of a disease than treating the disease. I'm interested in treating the disease. In private medicine, we treat first. In public health, we have to think about prevention first.

Contact tracing should be done. Partner notification and assistance. We need uniform standards for HIV disease reporting, frankly for all communicable disease reportings, and that should just be a condition of funding. So when the CDC gets the data, they know what it's worth.

The National Clearinghouse for HIV Reports. HIV is a permanent infection. It's worth spending the money and the technology to have a really good database, and you could use that database to make

sure people who are infected are getting treatment, know about new advances, know about things that are good for them. This is a two-way street. Being infected with HIV and not knowing about it is bad for society and it's bad for the individual.

We also need to start supporting public health law projects that increase the state's traditional disease control powers and preserve traditional public health law powers, rather than having even the government involved in projects that weaken public health laws. The government needs to understand that public health is not individual rights, it's community rights. It has to be respectful of individual rights, but that cannot be the only thing it's concerned with.

Now, one last thing. I've been doing a lot with bio-terrorism since 9/11 because I did some with it before when nobody cared about it except me and some folks at the CDC and anybody who really thought hard about what not having anyone immune to smallpox implied. We have plans in every major city about how we're going to do extensive contact tracing

and investigation to deal with outbreaks of smallpox, plague, other diseases. Frankly, nobody has the manpower to do it. At the same time this is going out, MMWR is reporting that the epidemiologists are being fired around the country because departments don't have the money to support the staff, positions are being filled with people with much lower skills, maybe no public health training at all.

Putting money into a national control program for HIV, which would require thousands of epidemiologists, tens of thousands of disease investigators, good data collection, would give health departments the actual infrastructure they need to do disease investigation, and it would answer the biggest problem with the bioterrorism plan, which is any plan that requires staff and resources that sits on the shelf until somebody blows the whistle will not work. The military planning folks are eloquent. If you aren't running people through the drill, if it isn't part of your everyday activity, you can't make it work, because you can't keep the people hired.

Health departments may have a bio-

terrorism plan that says they'll take care of things, because if they say anything different the health director will be fired, but the health directors know they don't have the staff for it, and the city won't pay them to keep the staff sitting around at their desks twiddling their thumbs. This could be where we fund the infrastructure to provide disease investigation capabilities again in health departments, and it's going to take us 10 or 20 years to make a big dent in HIV, and a lot of it is just changing the culture. But we get some real good side benefits. We'd have enough people to actually deal with other diseases, because health directors will tell you there are other things out there we wish we had the manpower to deal with.

Well, that's my 40 minutes, and we've got 20 minutes for questions because I'm a lot more interested in hearing from you than you may be in hearing from me. This presentation is available on my website. The link is in the handout, along with other materials.

Do you want to moderate?

DR. SWEENEY: I want to first thank you.

(Applause.)

DR. SWEENEY: You so eloquently expressed so many of the issues that we dealt with in our prevention subcommittee meeting last month or the month before that I'm sorry that we didn't have you at that meeting.

I am going to moderate by asking questions. But I do have to say, we are going to have to make sure, in order to give everybody a chance to get their questions out there and to stay as close as possible to on time, that we don't go on and on with our comments before questions. So please try and limit it. I don't have a way of gonging you at one minute or two minutes, but please just be mindful of your council members.

The first person that said to me while you were speaking that they wanted to speak was Lisa, Hank, Ted, Joe. I think I can put everybody's name down. Reverend Sanders, Jackie, Frank, and David. Okay, let me just do this to make sure I have everybody's name. It's Lisa, Hank, Ted, Joe, Reverend

Sanders, Jackie, Dr. Judson, and David. Did I get everybody? Thank you.

Lisa?

MS. SHOEMAKER: Well, my question is how I can jump on board and help in any way I can. I was one of six patients that was affected by a dentist in Florida, and when I revealed what happened, I was told not to tell anybody because of the stigma. I called everybody I had been involved sexually with myself, and then the CDC also contacted people that I could not get hold of. But this is something that I think is long overdue, and I thank you very much for your presentation.

MR. RICHARDS: You're the commission. Start talking about this. It's not been very fashionable in the past.

Before we go on, I'm also happy to answer emails if anybody wants to follow up after this.

DR. McKINNELL: Thank you for your presentation and, maybe more importantly, your commitment to this arcane field, which is becoming increasingly important.

I have two very brief questions. One is that sometimes I get the feeling I'm learning a foreign language, and you speak of contact tracing and partner notification as different things. I don't get the difference. So maybe answer that one and then I'll do the second.

MR. RICHARDS: I don't particularly either, but it became politically correct to separate some of the stuff. I lose track of what's the fashionable jargon at the moment.

Find them, warn them, investigate them. It should be a seamless operation.

DR. McKINNELL: Okay, we're on the same page.

The second is kind of, to me, the key question. We have somehow, in routine medical care, defined the standard of care. I don't know how we did that, whether it's in the law or medical practice, but any physician who conducted general medicine and did simple physicals but refused to do a blood pressure test would probably be driven out of practice. I don't know quite how, but why isn't a routine AIDS

test part of standard care and some physician who refuses to do an AIDS test or doesn't do AIDS tests, what are the consequences to that person? Can we connect this up to some accepted standard of care in the law or in medical practice?

MR. RICHARDS: Well, perversely enough in our society, we tend to set standards of care through tort law. I'm an old torts teacher, which doesn't mean I think it's the right thing, but I do unleash those herds of locust on you. For some reason, AIDS has not been an issue in tort law. There have been some cases holding physicians liable for not diagnosing HIV, absolutely. But when folks expose their partners to risk through HIV and docs don't test for HIV, it's like there's this blank spot in tort law, because in any other area with any remotely comparable risk, there'd be an onslaught of litigation. There's a lot lost in the history of torts and the politics of torts that's beyond our scope, but the answer to that is that tort law, to some extent, is the public relations, and it's been blind in this area; not that I'm advocating we

increase litigation.

DR. SWEENEY: I would just like to add to that. There's been a lot of confusion and lack of a clear message. In New York State for a very long time, physicians had the right to tell or not to tell a partner of a person, and a lot of discussion was that your responsibility is to your relationship with your patient, and you could do it or not do it without any penalty. It is much clearer now, and people do have the responsibility of notifying the state and either CNAP or PNAP contact tracing and partner notification for the city or the state when you have a positive diagnosis. So when the law became clear on it and there was no ambiguity, then it has to be followed.

DR. McKINNELL: May I follow up on that for one second? I see two different issues here. I think contact tracing is one thing. I don't practice medicine, but I don't know how you would practice medicine if you didn't do routine tests like blood pressure and cholesterol level and HIV status and 10 other things. That's my issue.

DR. McILHANEY: Just a quick thing. I think the standard of practice is there for a lot of things. For example, the standard of practice for gynecologists would be to do a Pap smear at the appropriate time. About 20 percent of women leave gynecologists offices who needed a Pap smear who didn't get it, and yet there's generally no lawsuits that come about because of that failure. So it's not a binding thing but just standards of practice, if that helps.

MR. RICHARDS: The fact is docs aren't very good at a whole lot of preventive tests. In that sense, they're worse with HIV because there are so many roadblocks to testing. So it's not like they're doing all the other things they're supposed to do, but they're busy.

DR. SWEENEY: I have to let Frank, who is the other practicing physician, have a word.

DR. JUDSON: To continue with the standards of care goal, the standards of care occur variably over time. The professional associations have a lot to do with it when they end up debating and

putting out recommendations. Law courts also end up, one way or another, deciding cases as to whether things were up to quality of care. But one of the most important determinants of a standard of care are now these national overriding organizations, like the National Committee for Quality Assurance, which supplies something called HEDIS, or the Health Employers Data Information Set. By the time it reaches that point, there's general agreement that something should be done at a certain rate to certain people. It may be testing sexually active women for chlamydia who are less than 25 years of age. That becomes a standard by which employers will evaluate the health plans that they choose for their employees.

So it would be the same thing now for offering hepatitis B vaccine to adolescents routinely. It's progressed through the Advisory Committee of Immunization Practices, onto NCQA and HEDIS. The same will be true for HIV. One would really hope that we're not very far away from routine testing for HIV in every new patient encounter where there's any chance of HIV at all. Hopefully, then, HEDIS and NCQA

would evaluate health care providers by whether they do this 90 percent of the time or 80 percent of the time or whatever is considered the standard.

DR. SWEENEY: Ted?

DR. GREEN: Thanks for a great presentation. I agree with what you've said. This focus on individual rights, not that they're not important of course, but at the expense of public health principles has not only harmed the United States, we've exported this approach to the rest of the world. For example, I was working in South Africa in the early '90s when that country was gearing up to respond to AIDS, and American and European advisors were helping guide that national response. Well, South Africa has the highest number of HIV infections in the world. It has one of the highest infection rates. There's a lot of casual multi-partner sex. It may lead the world in the incidence of rape. There's a lot of cross-generational sex, older men/younger women.

I read a report this morning that the government is recommitting to human rights. The focus

is going to be on human rights. Meanwhile, and I mentioned this yesterday, Jamaica has developed a somewhat different kind of response to AIDS. It worked out an unusual relationship with USAID and CDC in 1996 that basically said, "Listen, give us the money. Instead of most of the money going to U.S. advisors, we feel we have some good venereologists in the Ministry of Health, so give us the money and if we don't give you results in five years, then bring back your American advisors."

I was one of the evaluators of their program. One of the things they did when they were just given the money and allowed to prevent AIDS as they thought best was contact tracing and partner notification. I mentioned yesterday this was done in a way that didn't out anybody or compromise anybody's anonymity. Jamaica was seen to have pretty much the same kind of risk factors as South Africa, maybe with less rape. Infection rates were about 1 percent instead of about 25 percent, and STD rates have been coming down. They do contact tracing and partner notification for STDs, and HIV is considered another

STD.

So here is a country doing what you're suggesting ought to be done, and we're seeing good results. Thanks.

DR. SWEENEY: Joe?

DR. McILHANEY: I just wonder how you've been received when you've presented this to different groups around the country. It seems so reasonable.

MR. RICHARDS: First, I don't get many opportunities to talk about it because it seems so reasonable.

DR. McILHANEY: That's sad.

MR. RICHARDS: More generally I work on the larger scope of public health powers. This just happens to be the one where the problems and the disease have been so closely linked. Until 9/11, public health in this country, both at the state and federal level, was dominated by the personal medical care concerns because that's the way the politics worked. It's ironic, the anthrax letters posed no real threat, but they galvanized the country, and suddenly traditional public health, the notions of the

state needing to protect you, were revitalized, the way they were up through 1970. So I've gotten a lot of chances to talk, although mostly on bioterrorism, which I have a lot less cheerful things to say about.

I keep telling health departments, "Don't worry about obesity, don't worry about bio-terrorism. If you can't figure out how to solve a communicable disease that's infecting more than a million people, work on that." Anything you do to make that work will help everything else you have to do.

DR. SWEENEY: Reverend Sanders?

REVEREND SANDERS: First, let me say thank you very much for the presentation. Clearly, you bring a great degree of passion to what you have to say.

I spend my life as a messenger, and I think you have a very important message. I want to say some things about the message. I've always said that I thought that AIDS was going to be the vehicle by which we would be able to solve many of the complex and painful problems that exist within our society, because it forces us to deal with issues that we have

denied, tried to avoid and not deal with forthrightly.

To that end, one of the things that I found to be of some concern as you did your report and made your presentation is when you give an historical analysis, I think there's a bigger picture. I think it is AIDS, I think it is what was going on in the gay community, but I think the larger historical perspective is the era of civil rights, and I think the way in which many people ended up with the language of Title VII and "suspect class" and that kind of thing ends up being the byproduct of historical discrimination, and the ways in which people have legitimate rights to fears and concerns as to how they might be treated within society if indeed they did not have some legal protection.

Let me put it like this. Where you ended up, we would not argue in terms of how public health needs to be done. How you got there is a different issue, because I think how we get there in dealing with it forthrightly is a part of how we deal with some of the issues that I think haunt us in this society. So ultimately you have to deal with race and

class, you have to deal with gender discrimination, you have to deal with those dynamics that have translated into the kind of stigmatization that have caused some people to be compromised in terms of their ability to realize the full potential of the American dream.

So I appreciate that, but the backdrop is -- I mean, for instance -- and I'm sure this was the quick version, so let me preface this by saying that. But I find it very difficult to give an historical backdrop, especially as it relates to where this disease is going today and the change in its complexion, and you did not even mention the word "Tuskegee," because I think that in terms of folks who have suspicion and people who have distrust and people who have concerns, then you'll understand why there was some, perhaps, propensity towards leaning in what ended up being a hurtful direction in terms of this whole issue of -- and I think you're right in terms of the whole question of how you deal with exceptionalism. But I think there's a way in which you have to appreciate how that came to be.

I guess the last thing I would want to say is that I think it's very important, and we've got to move aggressively, we've got to move quickly to deal with the whole issue of bringing to bear the best public health strategies that we can to deal with HIV/AIDS. But I think that we have to make sure that as we do that -- I'll give you this example, and then I'll stop.

When you come to where we were in the 1960s and '70s, the scales of blind justice were clearly tilted in a way that represented a kind of discrimination that had to be addressed. What we've seen to some degree is a correction. Whether we over-correct or whether in the process of correcting we end up compromising some of the principles that I think are solid, sound, and had to be used in terms of public health, we have to understand how we got there, and we have to make sure that justice remains blind, because there are a lot of instances that translate into why we have the disparities, and the disproportionate impact of disease upon some communities versus others has a lot to do with the

fact that the lady is peaking out from under her blindfold.

MR. RICHARDS: I couldn't agree more and in the long version develop the same issues, the role of Tuskegee, the role of race in HIV. I mean, maybe I didn't say it strongly enough. If poor black women in particular, who are the most difficult -- they're getting the biggest risk for HIV right now, were more politically powerful than gay men, the whole shape of this, the epidemiology and the laws and the services, would be entirely different. Race is the giant issue in this, race and class, poor women, poor men, minority communities, and it comes from all those things you talked about. If we're doing the two-hour version, you'd love it.

REVEREND SANDERS: Thank you. You're an important messenger. I think we're going to help to make sure you get to carry that message. We're probably going to include that message in some of what we report out from this committee, but I would hate for our report not to reflect the kind of historical backdrop that I'm trying to suggest, because it

undermines our ability to turn HIV/AIDS into, I think, an important response to a lot of other stuff in our society.

DR. SWEENEY: But the exceptionalism actually started before the epidemic moved to the powerless. So it was not based on race and class then.

MR. RICHARDS: The exceptionalism started partly around the whole rejection of support for public health as people quit worrying, but also around the political issues in the gay bathhouses. But that didn't change when we suddenly realized that there was this huge dimension of other folks at risk.

DR. SWEENEY: Jackie?

MS. CLEMENTS: Thank you. I am an HIV pre- and post-test counselor in my other life, my real life. I want to first say that I do believe in routine testing. I do believe that with regard to HIV, the rights of the public should outweigh that of the individual. I would even say do away with pre- and post-test counseling. I'd find another job if that would make a difference.

However, pre- and post-counseling also, especially pre-test counseling, is an opportunity to gather some information. I think that in your presentation, you might include that providers, primary care providers would need to have some training, some retraining in HIV and testing, simply because there have been numerous occasions when a provider has asked me about -- couldn't find a result in a chart, and I looked, and it's there, and I said in 2004 she tested negative, and he goes and says, "Oh, she's negative." That's not what I said. I said in 2004 she tested negative. There is a window period, a three-month window period, oftentimes forgotten. You know, I had sex last week, you test me today. We've got to consider a three-month window period, and a lot of people who do not deal with HIV, primary care providers, don't consider that.

So in your presentation, consider that there would need to be some retraining in order to do routine testing and ensure the validity of the results that you're getting from your testing.

MR. RICHARDS: And I don't disagree. Dr.

Judson really went to the heart of that. I'm really talking about removing the barriers, but it's going to take professional standards and professional education to allow docs to take advantage of this if we remove the barriers.

DR. SWEENEY: Dr. Judson?

DR. JUDSON: Well, Ed, that was terrific, as I've learned to expect over the years. I think that was a perfect response to the question that was raised by the Prevention Committee regarding a key component of how we would hope to reframe the whole prevention approach to HIV. Part of that has to do with the law, which I think you very eloquently and completely covered here. In fact, we might take your last three slides and use them as the component that would tie together reauthorization of Ryan White and certain other federal programs. It speaks to each of those issues.

There have been many missed opportunities, but we have another one coming up now, and that's to make sure that all federal funding is pushing in the same direction towards prevention and control,

supports prevention and control at every level. We were also hoping that it might be possible, through CDC leadership or other leadership, to come up with the model laws, or at least the standard components of modern law towards public health control of HIV, and that would very clearly include name-based HIV reporting on a national basis. It would start with the states, but it would be plug-to-plug compatible all the way up.

So we know what's happening now and not 10 years ago. It's the same thing we've been saying, you and I and others, for 20 years, that if you don't know who is infected and who is exposed, you can't control any critical infectious disease.

As far as the civil rights go, we've also been saying for 20 years that, yes, this is a civil rights question. It's a question about the right to life and pursuit of happiness. You can't do that if you're dying of an incurable viral infection which could have been prevented. So what is threatening the human rights and civil rights of individuals in this country is simply a little piece of DNA and RNA that

will kill you eventually.

DR. SWEENEY: Thank you.

We have David Reznik.

DR. REZNIK: As is so often the case, the Reverend Sanders expressed many of my concerns in a much more eloquent fashion than I could. I would, though, like to look at the outline and the history of discrimination that did face people with HIV and AIDS in the '80s and in the '90s, which was a real thing, a very real thing, which is why I got involved in this disease to start with, because people were denied access to oral health care, people were denied access to housing, people did lose their jobs, people did lose their homes, people weren't allowed to visit people in the emergency room. There was an issue back in those days.

I think there is still an issue today. I think it's affecting a different population, and still some of the traditional population. With that being said, I still think we need to go to a much more proactive name-based reporting and much more health-centered model that we're talking about. But I don't

want there to be any diminishment or lack of emphasis placed on the many people's lives that were impacted by this disease the first go around. I mean, the issues of discrimination, the issue of lives being ruined, both those impacted, infected or affected, were real.

I do believe that we need to go to a public health model, having said that. So that was just my comment.

MR. RICHARDS: And there have been some major changes. The Americans with Disabilities Act was to some extent driven by AIDS discrimination. There are a lot of other issues to it, but that act is now in place. The HIPAA privacy, we have a much stronger and federal framework for protecting individual rights.

DR. SWEENEY: I've been told that we are over time, but we have two burning, short, and then the last two. Joe, then Reverend Sanders, Dr. McIlhaney, and that Joe.

Reverend Sanders, very short, and then back to our co-chair, Anita Smith.

DR. McILHANEY: I'm on Dr. Gerberding's advisory committee, the director of CDC, and I was speaking with her yesterday evening after a meeting. I asked her twice if I should tell you this, and she said yes. She said tell him to keep it quiet, though. With the audience, I don't know how quiet that will be. But anyway, she said that they are moving ahead at CDC with advancing HIV prevention, and she just wanted us to know that that process was moving, and so she was happy about that.

I don't know if after this discussion we're going to have to go back and say, hey, you need to change it again or not, but at any rate --

DR. SWEENEY: Reverend Sanders?

REVEREND SANDERS: I guess I just wanted to be sure to say that we still live in a world where people are very prone to use scapegoating as a way in which they're able to move quickly to justify doing all kinds of things, and for that reason I don't quickly dismiss any issues that compromise the question of civil rights.

A perfect example is if you take Dr.

Richards' presentation, especially as he talked about if you had closed gay bathhouses down at a certain point, we wouldn't be where we are today, you tread on shaky ground when you start isolating an issue in a way that fuels the fire of people who would say things like this is a curse from God. You just have to be very clear that the message is always balanced.

I would hate for the disease -- at least gays can go and pretend to be straight. At least Jews can go and pretend to be German. As this disease changes its color, the last thing I want is any scapegoating availability to exist for folks that would allow you to be able, on the basis of the color of your skin, to be able to say you're the problem. Now, you could probably end up with a lot of analysis about what you could do in communities of people of color right now that you could argue would change the disease as it's manifesting itself in the future. We've got to make sure that as we develop solutions and responses, that it does not lend itself to that propensity in human nature to use any group of people as a vehicle by which they scapegoat and then justify

injustice in relationship to those people.

I think that's what gays were dealing with, and I think that's where we are in terms of people of color today.

DR. SWEENEY: Thank you for that, Reverend Sanders.

I want to say again how much we thank you, Mr. Richards, for an outstanding presentation. You see the heat and light that you generated around the room. Thank you very much.

MR. RICHARDS: Thank you.

(Applause.)

MS. SMITH: Thank you.

We are, as Dr. Sweeney said, running a little behind, but we're moving right into public comment now. We had two participants yesterday who had signed up, and we have some more today who are in the audience. What we're going to do is Joe Grogan will be reading the names of the folks who have signed up for public comment, and we'd ask you to come to the microphone at the time your name is read and make your comment. Thank you.

MR. GROGAN: Thank you. You have three minutes for public comment, and I will notify you when you have 30 seconds left and when time is up, and we're going to be firm as to when time is up to keep this moving.

The first person on my list is Diana Bruce. Is she here?

(No response.)

MR. GROGAN: Robert Burns?

(No response.)

MR. GROGAN: Gene Copello?

DR. COPELLO: Good morning. I'm Gene Copello from the AIDS Institute. I have just three brief comments.

The first is that I want to encourage the Council to continue the discussion that you had I believe several meetings ago about encouraging the White House to convene a White House conference on AIDS. I don't believe you've discussed that recently. With so much happening in prevention and care and research, I believe that that would be an important meeting. There hasn't been one of that sort since the

1990s. So I would encourage you to continue with that recommendation.

Second, I understand yesterday that there was some discussion about PhRMA and PhRMA's donations to prevention programs. I just wanted to comment that we hear often today, including from the administration, the importance of dealing with this epidemic from all sectors, the private sector, the government sector, the non-profit sector, and just to comment, several pharmaceutical organizations have indeed provided funds for prevention activities. One major example is Pfizer, which funded $3 million to 24 agencies in the south for basic prevention services in a region that really needs those kinds of services. But there are many other examples.

So I wanted the record to reflect that, because those agencies across the country need that kind of funding from the private sector, and it should be encouraged rather than discouraged.

My final point is I believe all of you have received a copy of the reauthorization position paper from the AIDS Institute electronically, but

there are copies outside with the staff if you don't have one.

Thank you very much.

MR. GROGAN: Genevieve Grabman?

(No response.)

MR. GROGAN: Lance Hogg?

(No response.)

MR. GROGAN: Brent Minor? An old friend.

MR. MINOR: Old?

(Laughter.)

MR. MINOR: Good morning, my friends. I'm glad to join you and see so many familiar faces around the table. Let me begin my comments by saying how honored I was to serve with so many of you during my five-year tenure on PACHA.

I'm here today as a member of the board of the Federation of Gay Games. As some of you may know, the Gay Games are an international sport and cultural event that have been held every four years since 1982. Since then, thousands of people, including over 11,000 at the 2002 Gay Games in Sydney, Australia, have lived out the three principles of inclusion,

participation and personal best on which the Gay Games were founded. The 2006 Gay Games will be held in Chicago, and organizers estimate that over 12,000 people from all corners of the world will participate.

The reason I'm here today is that some of those athletes and artists will be people like myself who are HIV-positive or living with HIV and AIDS. As you know, the United States has a law that requires people with HIV to receive a waiver in order to enter the country. In order to comply with the law and lessen the stigma that HIV-positive travelers may confront, the organizers of the Chicago Gay Games are making a request of the Department of Health and Human Services to receive designated event status, or DES, for all foreign HIV-positive Gay Games participants during the 10-day period that the games will be held.

Designated event status has been given numerous times over the years to various meetings and conferences, including the 1994 Gay Games in New York City. I want to take this opportunity to alert you that this request is being made, and I hope that PACHA members will consider, either as individuals or as a

whole, supporting this request. There is strong bipartisan support from members of the Illinois Congressional delegation on this issue.

Granting designated event status for the Chicago Games would not change the HIV immigration law in any respect. Indeed, the same requirements of not becoming a public burden would apply whether the participant received an individual waiver or entered the country under the blanket waiver through the designated event status. The DES simply allows travelers who can demonstrate that they are participating in the Gay Games from seeking an individual waiver. This will help encourage people with HIV to participate more freely and with less stigma.

I have been active in gay sports for a number of years and have completed 34 Olympic distance triathlons and two marathons since my own HIV diagnosis. I see sports as a healthy and positive alternative, not just for gays and lesbians but also particularly for people living with HIV/AIDS. I feel that the kind of experiences offered by such events,

such as the Gay Games, help people feel better about themselves and their community. I know it has helped me and feel that it can help others.

Thank you for your time, and I will be happy to speak with any of you further about this. I think you all know where to reach me. Thank you. My copies of my letters to Dr. Beato and my comments are out on the table. Thank you.

MR. GROGAN: Thank you, Brent.

Last we have Connie Jorstat.

(No response.)

MR. GROGAN: That's all I have on the list that was here. Was there anybody --

MR. RUSSELL: I was on the list originally.

MR. GROGAN: Okay, we have time.

Can you state your name and your organization?

MR. RUSSELL: Yes. My name is Randall Russell. I'm with the Southern AIDS Coalition.

Good morning and thank you for allowing us this opportunity. The Southern AIDS Coalition emerged

from community-based crises in a region of the United States with the most new cases of AIDS, the largest proportion of waiting lists for persons in need of life-sustaining medications, the region with the highest disproportionate infections in communities of color, and a region with a wide geographic expanse comprised of less urban settings for the population. It's my honor to serve as the director of the Southern AIDS Coalition. We have several hundred members in 14 states and the District of Columbia.

The reauthorization of the Ryan White CARE Act must occur in a manner that, if possible, holds harmless all areas of the country as this federal tax-supported program strives to achieve a distribution of resources that ensures care and treatment in an equitable manner from coast to coast.

In 1990, Congress and President Bush's administration achieved a remarkable feat. They found a method to address a burgeoning infectious disease with staggering stigma and, at the time, mostly fatal consequences. Fifteen years and billions of dollars later, we stand on the shoulders of those who came

before us, who risked life in pursuit of science, risked social rejection due to misunderstanding and fear, and bravely confronted what most of us have the luxury to avoid facing, our obvious ultimate fate, an end to our life as we are able to now know it.

What has happened to our courage to do the right thing? Have we come to actually debate what is the right thing to do with federal resources when it's clear at present it isn't fair? How can we consider other alternatives than a fair distribution of resources to meet 100 percent of everyone's treatment and care needs supported by comprehensive care? No one of us deserves less than any other, and certainly no region deserves to be overlooked due to population distribution based on geography, history, and availability of resources.

Why in 2005 is it okay to double count cases in federal formulas for a few selected urban settings? Why are 19 states, 8 of which are in the south, left with the inexplicable burden in many cases to serve the same number of people with less Ryan White money than other states? Why are similar-sized

populations and the numbers of living cases of HIV/AIDS seen as less when it comes to disbursement for people in less urban settings?

All people with HIV who live in the United States deserve access to a full formulary with at least a minimum eligibility of 300 percent of the federal poverty level, and a guarantee in the richest nation in the world to not have to wait for life-saving medications, with access to full care and housing.

Attention also must be paid to increase prevention funds that go beyond abstinence when necessary and result in honest programs about behavior and consequences, and the actions especially of our youth in all communities across this great land.

Your leadership and our inborn will to do the right thing, our conscience, our collective conscience, must guide us to recommend to this administration that it's time to bring a quality of funds to care and treatment for individuals and families who struggle day in and day out living with a disease that continues to be more treatable, but only

if one is fortunate enough to live in the right part of the country. This wrong can be righted with an exercise of courage and will. That shouldn't be that hard, especially as we remember those who fought for initial recognition by the federal government to care for us.

MR. GROGAN: Time. Your time's up. Thank you.

MR. RUSSELL: Thank you.

MR. GROGAN: That's it for public comment. Before we break real quickly, I wanted to have Miguel Gomez make an announcement about testing day, and I believe a member has a comment.

DR. McKINNELL: I just wanted to underscore the important work of the Southern AIDS Coalition. In fact, it was Gene Copello's presentation here almost two years ago now, the Southern AIDS Manifesto I think it was called, but it convinced me that we had a problem, and I thought the answer was in partnerships, which is what led Pfizer to step up to more commitment to the area of prevention, contrary to what some people might think

about our work.

But I am particularly troubled by the latest CDC data. The southern states as generally defined are a third of the population, but 76 percent of new HIV infections in women are in the southern states. So if you combine women in the south and minorities, we have a real crisis that I don't think is getting the attention it deserves. Now, it needs funding, it needs partnerships, but to Reverend Sanders' point, I think it also needs messengers, that we do need trusted leaders in the community to feel like I do, and I'm sure they do, but we need them to be clear and vocal on the clear and present danger that exists to minority women in the south.

It's just incredible to me that there's probably three times the risk if you're a minority and a woman in the south than anybody else in the population, and that should just be unacceptable to us on moral grounds.

MS. SMITH: Thanks very much for the comment, Hank. I completely agree, and I think as a follow-up to yesterday and what you're just saying,

when we have our discussion over lunch, we were hoping to craft a resolution of some sort that would include the thoughts you just expressed. Thank you.

Thank you all for your public comments. We really appreciate hearing from you and taking the time to be here with us.

Miguel?

MR. GOMEZ: Good morning. Joe last night asked me if I could just provide a brief update on National HIV Testing Day and some of the things that are happening generated from Health and Human Services. So thank you, Joe.

What I'd like to do is just share that just so everyone knows next Monday, June 27th, is National HIV Testing Day. It's the 11th anniversary of the observance, which we here at HHS actually do believe is a tool to actually increase awareness and get more people tested and link them to care.

The theme for HHS is "Then and Now: Twenty Years of HIV Testing." I'll just very quickly tell you about some global goals for National HIV Testing Day, and then talk about some internal and

external things that are happening here at HHS, and then a small call to action, both for the audience and the PACHA members themselves.

Globally, this is just one tool to help us normalize HIV testing, to encourage individuals to get tested, hopefully early, and link them to care, and then perhaps even give us an opportunity to talk about the Ryan White CARE Act, which many of you are anxious to hear about, in a few minutes.

One thing that I'd also like to acknowledge is that the National Association of People with AIDS, in partnership with Health and Human Services, takes a lead in coordinating activities around the United States for this day, and there are multiple themes for this tool: "Now and Then: Twenty Years of HIV Testing," "It's Better to Know." Unfortunately, some focus groups recently told us it's better to know what? Also, another theme is "Take the Test, Take Control." Well, people asked, what test?

The Kaiser Family Foundation is using "Knowing is Spreading." Knowing your HIV status is an essential part of prevention and treatment. Again, we

have to reassess the themes, but what's important globally is encouraging HIV testing, taking away the stigma, linking people to care. Here at HHS we're providing that information through employee education events here. But what's also important is we're very proud that the CDC is launching a series of op-eds through partnerships and with the director of the CDC, getting the message out and doing some media tours.

What's also important is that the CDC has launched a very important webpage which, for a webpage, has an unusual quality. It's easy to use. It's called hivtest.org, and it doesn't say .gov, very important. All you have to do is put your zip code in and it will tell you areas in which HIV testing is available in your community. Very, very important. Also, there's a handout on a webpage launched here at HHS over a year ago that provides information for all HIV testing days. It's housed at the Office of Minority Health, and it also promotes the multiple other HIV/AIDS awareness days, from National Black HIV Awareness Day to, most recently, National Asian and Pacific Islander AIDS Awareness Day.

As I mentioned internally, we're also working to educate our frontline staff. In our employee education event activity, what's important is I just want to share one of the pieces from the document we're going to be sharing. By offering testing to all persons instead of those who "seem at risk," health care providers can help reduce stigma and ensure that all persons with HIV, if they think they're at risk or not, have an opportunity to learn their status. Stigma around HIV testing remains a concern. Over 30 percent of people tested report that they think people would think less of them if they found out they had a test.

So one of the things we will continue and we've done in the past, we're offering here at HHS is offering our employees HIV testing, and we do that multiple times during the year. What's important is we want to actually -- and we send the messages from our health clinic. We want them to think of an HIV test as something I should do like a flu shot.

One thing that's also important is that we're also putting posters up, hopefully, at the

health clinics on the Hill to encourage staff members from both the House and Senate to come over to HHS, if they wish, to get an HIV test. We're also encouraging other local organizations in the area that do have access to testing to offer it to their employees.

One thing that's also important here at HHS, we do promote our webpages, resources, fact sheets, information, but twice a year we do faith and civic events. Most recently we were in Deerborn, Michigan having our first Arab and Muslim HIV testing day event. Dr. Deborah Parham-Hopson, who is with the Ryan White CARE Act, the director, she was the keynote speaker. But it's so important to us, so we do this in conjunction with our faith office here at HHS. We have received some criticisms that often our faith-based events are within the Christian denomination and not outside that tradition. So we're very pleased that we held our first Muslim and Arab event.

What was so striking is that we had both our public health officials, our civic officials, the school board, and amans. We had over 70 leaders in that community, and what the leaders and participants

told us on the evaluation what made a difference for them was having their faith leader in the room declaring that HIV is an issue they must respond to in their community.

One last tool we have is that we encourage all of our partners on HIV Testing Day to send their staff and colleagues' emails just giving folks facts about the new CDC stats, but importantly, just telling your employees and colleagues that you'd like them to learn more about testing and perhaps get tested. I'd like to actually laud Joe for sending an email to all the PACHA members, a sample email that they could send to their networks. We'd be more than willing to actually provide sample emails to anyone in this room.

Again, HIV testing day is just one tool in the fight against HIV/AIDS. Joe, I'm glad you asked for an update. There's more information at the back of the room for folks. Good luck with your day.

MS. SMITH: Thank you so much, Miguel.

At this point we're going to take a break before our next session. We are going to cut the break to 10 minutes rather than 15, so we'd like to

see all the members back at the table in 10 minutes. Thank you.

(Recess.)

MS. SMITH: We'll move into the next part of our program, which is really something of interest to all three committees that have been working on the issue, primarily Treatment and Care and Prevention on the Ryan White reauthorization. Our discussion today will be with Carol Thompson, who is the director of the Office of National AIDS Policy, and Joe O'Neill, who is the senior advisor to the Domestic Policy Council. They both have experience with the Ryan White reauthorization in the past, and we're privileged to hear from them today in terms of an update. Also, I think the discussion will range into some other prevention issues that we're interested in delving into with them and hearing their thoughts about.

So we'll turn the time over to Carol and Joe.

MS. THOMPSON: Good morning, everyone, and thank you all for joining us this morning. It's

wonderful to be here. It sounds like you guys had a very full day yesterday and have had some interesting discussions this morning.

We wanted to take a little bit of time this morning to give you a brief update on Ryan White reauthorization and the administration's principles that are going to be coming out.

I wanted to take one minute briefly to acknowledge and say thanks to a couple of folks. Deborah Parham is here, Christopher Bates is here, Marty McGeein is here, and they and a lot of staff at HHS have been working very hard on looking at the program, looking at the bill, and really looking at best ways to make improvements and changes that will really help us reach those that are in greatest need.

As far as from the White House, we are very, very, very close to finalizing principles that we would like to release as soon as possible. We know that the Senate has been looking at the bill, and we know that the House has been focusing primarily on NIH reauthorization, but I know that they are very aware and very interested in working on a bipartisan,

bicameral basis to get the bill worked out with the Senate and hopefully passed, and get something to the President in due time. Obviously, the bill ends in September of '05, and ideally the President has stated several times, including in the State of the Union, that he is anxious and interested in reauthorizing Ryan White. So that's what we're all working towards.

I would probably ask for your patience for a little while longer, but we're close to finalization, and you'll certainly know as soon as possible if we can get those principles out.

We can certainly take a couple of minutes if you all have any comments that you have on Ryan White, and after that I thought we would move to talk a little bit about prevention in the context of Ryan White and outside Ryan White.

DR. O'NEILL: I think one of the things that is really important to say is that one of the reasons that we still haven't finalized and put into stone the principles is that we wanted to have this conversation with this group. We've met multiple times and iterations where we've talked about this,

but you've received a lot of new information over the last couple of days, some very important information even this morning, and we did not feel it was timely to have moved forward until we had one last opportunity to really sit with you all and have a discussion and hear feedback. So here we are.

MS. THOMPSON: Yes, sir?

DR. REZNIK: I have a question that is related to the CARE Act but it's not necessarily direct. The President came forward last year with a $20 million initiative to help eliminate the waiting lists for ADAP, and that initiative is going to run out in September. There are 1,500 people who are benefiting from the initiative, which we're all very grateful for. Are there any plans on how to address what happens when the funds run out in September?

MS. THOMPSON: Is anyone here from OMB?

(Laughter.)

MS. THOMPSON: We're very much aware of the timetable for those folks, and obviously with the overall goal of trying to reach more and more people who are in need of medication. We're certainly

working on making sure that we're able to continue their treatment.

DR. O'NEILL: I think that announcement, the President's announcement of the $20 million was in the context of his speech where he also called for Ryan White reauthorization and called for a number of concepts in the reauthorization. The thread that runs through that is that this was a short-term fix, but the real fix for focusing our resources and organizing our resources so that we don't continue to have waiting lists has to do with taking a serious look at the Ryan White CARE Act.

So I can tell you, finding that $20 million was a heroic effort on the part of HHS and OMB and HRSA to do that. It's no way to run this business, which is why the Ryan White reauthorization is so important that we actually all have to grapple with the issue. What kind of a country do we -- how do we want to respond to this? There's an appropriations process and there's an authorization process, and this is the time we're looking at authorization. So if the conversation degenerates

into just more money and not looking at how we spend it and how we organize it, we're not going to have a fruitful conversation here. So we're taking that very, very seriously, to look at the authorization first and how do we structure our resources in such a way that we have equity and focus and we're not into these kinds of situations.

DR. REZNIK: Can I just follow up briefly? The only reason I wanted to follow up is because I know the reauthorization timetable has been pushed back a tad. Originally I think the Senate wanted to get something done by the end of September, and it looks like that's not going to happen. I understand that we need to address, and hopefully the administration and the House and the Senate will address the ADAP crisis on a long-term basis. I'm more worried about the short-term problems in North Carolina and Alabama. I don't need to know the specifics, just that the administration is aware that we have a problem and there's a time gap there and that we can somehow manage to figure out a way to pull a magic bullet out and help those people. That's all.

DR. YOGEV: There is a new population that is emerging in this disease which is running into problems because of maybe state laws and the like, which is the adolescent. We now have a whole population who were able, through Medicaid, to bring to the point that they are adolescent, and at least in two states -- one of them is mine, Illinois -- that I'm aware of, you have to have AIDS to get services when you're 18 and older. Basically what happened is we just dropped those patients because there's nothing to pick them up, no sufficient funding specifically for a population which is growing. I'm sure you're all aware that this is the second fastest growing population that has no work, no insurance and can't get Medicaid. I wonder if that's part of the new reauthorization of Ryan White.

MS. THOMPSON: I'm not sure. It's a problem that hasn't specifically come to my attention, that once you turn 18, if you're HIV-positive, that's not enough, that you have to have AIDS to get care.

DR. YOGEV: Yes, paid-for care.

DR. O'NEILL: It raises a number of

important issues. First of all, states approach this differently, and states contribute different amounts of resources themselves. For some of these issues, they're different from state to state, and that's one of the important elements that needs to be kept in our minds. The second thing is that there are particular components of Ryan White that do specifically focus on adolescents care. The third point is that the interdigitation between Medicaid and Ryan White is an extremely important issue and one that is ultimately going to be solved by a federal and state partnership to look at those issues.

Finally, the federal government is a very blunt instrument to solve a particular problem in a local jurisdiction or in a particular state. I think our job is to create the environment by which state and local expertise and communities and governments and people living with AIDS can work together to figure out how to solve these problems in the appropriate way for various communities. But there are as many different problems and populations like this as there are states and communities, which is why

the structure of the CARE Act is that it allows different communities to respond differently. That's an important one.

MS. SMITH: Frank?

DR. JUDSON: In formulating the principles guiding Ryan White reauthorization, some of the ones that we've discussed are really all directed at not accepting the status quo of simply every year adding 26,000 new cases who need to be treated. That's the number of those leftover after 16,000 to 18,000 die and you have 40,000 to 44,000 new cases.

The principles are for a patient receiving Ryan White funds from his fellow taxpayers or her fellow taxpayers is that "HIV stops with me." The principle for the physician who is taking care of patients who have HIV is that "HIV stops with my patient" and you'll do everything to understand whether there is a risk of ongoing transmission. For states that receive federal Ryan White monies, a requirement that we've tried to have placed in these laws since 1993 or 1994 on is that the states must have, as a condition for receiving Ryan White money,

name-based reporting systems in place, and they must use that information to understand how the epidemiology is changing and to most efficiently apply their limited prevention dollars to preventing new cases. For two or three authorizations in a row, that day has continued to be put off. So I think prevention just needs to be as tightly tied and conditioned as possible on federal funding.

MS. SMITH: I just wanted to say I have two more questions or comments on Ryan White, and then we can move the discussion to prevention. Joe needs to leave at 11:00, so we want to be sure to have him as part of that discussion.

So Joe McIlhaney, and then Dr. Primm.

DR. McILHANEY: Frank is always so eloquent, but what I want to ask bears on what he said. Are you at liberty to talk about what prevention efforts might be a part of Ryan White or your conversations about that? If not, that's okay.

DR. O'NEILL: I think it would be more helpful to hear what -- I mean, like I said, we've certainly given a lot of thought to it, and as you

said, it's been out there every reauthorization, the last couple of reauthorizations, a prevention component. So I think it's certainly something that's of great interest to us, and I'd be most interested in using this time to hear from you about what elements -- as you formulate your recommendations or thoughts on this, what elements, if any, which I assume you've got some ideas on this, that we get that out there.

But sort of backing up to the 50,000-foot level, we need to look broadly at USG policy, I think recognizing that our response domestically is part of the global response, number one. The world is looking to us as models of the way to do things. So what we do in terms of public health becomes, I think, very important.

The second thing is that we have to look not just narrowly. There's care, treatment, prevention, research. How do these things come together? Clearly, if we don't have some serious impact on the prevention of this illness, Ryan White is never going to be big enough. We're fighting a losing game here. How that works out legislatively is

another question. But clearly, knitting together care and treatment and prevention and having the conversations between these stovepipes is extremely important.

Parenthetically, when we're designing PEPFAR, one of the things that was very important to me was let's not make the same -- let's try to -- if you remember the model of an integrated system, a network system for integrating care, treatment and prevention, which is embedded in PEPFAR, really came in my mind as a reaction to what I think was a flawed approach, that we've approached these things domestically in very separate categories. That's why I made the initial comment about looking to the domestic response as part of the global response, because I think there's a lot of interchange back and forth. I think we learn something from the domestic work that came into how we design PEPFAR, and I think we're going to learn stuff in PEPFAR that may come back and help us do a better job thinking through how we respond domestically, because ultimately we're all human being struggling with this virus and struggling

with our good angels and bad.

DR. McILHANEY: Well, that's good reassurance that you're thinking about incorporating prevention into the program.

MS. THOMPSON: I don't know, Dr. Primm, if you want to say something else about Ryan White, but we do want to say a little bit more on the prevention piece, which is having been at CDC -- I think, Dr. Judson, I think it was you who said we can't treat away the disease. We're very much on that line, which prevention is really a central focus in, as Joe said, a comprehensive approach to fighting the disease, and we are leading by example. So as we ask other countries, other nations to implement voluntary counseling and testing throughout --

DR. O'NEILL: And just to build on that -- we could just talk to each other all day.

(Laughter.)

DR. O'NEILL: In the last two reauthorizations, there was no administration position, official position on reauthorization. This time we've got a President who has talked about it

twice, once in the State of the Union address. This is important, and the linkage between what's happening between prevention and care is extremely important. The routine HIV testing, the President has talked about routine HIV testing already, on June 23rd of last year. It's a challenge to all of us.

MS. THOMPSON: Voluntary.

DR. O'NEILL: Yes, always voluntary. But moving and integrating -- we've got to end this thing. That's the point. We have got to end this epidemic. A continuing pace of 40,000 or 50,000 new infections every year does not look like ending to me.

MS. SMITH: Dr. Primm?

DR. PRIMM: My point was that the Treatment Committee of the Council passed a resolution a couple of meetings ago that was unanimously voted upon that any monies that are out there, prevention or treatment monies, Ryan White reauthorization included, that it follow the epidemic, that African Americans and Hispanic Americans is where this whole problem today is focused primarily, and what Hank just talked about in terms of the southeastern United States, and

what the President talked about in his State of the Union message, about reauthorization of Ryan White and what's happening with African American women.

I think we need to take that into strong, strong consideration as we talk about these issues, that it follows the epidemic, that the money goes where the problem is. I'd like to make sure that this committee sees that, and that the White House sees that that happens.

MS. CLEMENTS: I was going to say exactly what Dr. Primm was saying.

DR. McKINNELL: Well, Carol and Joe, I applaud you for coming to talk about what you can't talk about. You're doing a fine job so far.

(Laughter.)

DR. McKINNELL: You asked us for the 20,000-foot-level analysis, and I've been pushing this group, maybe too subtlely, to ask a different question, and I would really encourage you to put a small group of really good planners and strategists together to provide a comprehensive strategy. Strategy would be, if our goal was an AIDS-free

generation by 2020 -- you pick the date -- what would we do? We're setting out to win a war, and you don't set out to lose, you set out to win. I don't have a sense of a winning strategy here, and the goal is pretty clear. It's eliminating this virus.

Now, that's going to take many hands and many generations and many dollars. But if we don't have a strategy, we won't get there. When you have that, then you need funding and partnerships and five other things. But I think it all starts with the strategy, and I really think that has to be articulated by the administration.

REVEREND SANDERS: I don't know if we're ready to transition a little bit into prevention. I guess I want to speak to the issue of Ryan White and prevention at the same time.

I don't want there to be the misnomer that prevention is not already happening within the context of Ryan White, okay? Some of the things that are happening in that regard, especially as it relates to the way in which I know in Title III and some other instances we've had the opportunity to build capacity

in communities that need desperately to be involved in the response that we're trying to formulate is very significant.

I think the issue for us is going to be -- and this kind of opens it up in terms of the issue of prevention and Ryan White. The issue then ends up being for us how we define the scope of prevention in the context of care and treatment. I don't think that they are mutually exclusive, as you suggested a minute ago, but I don't think we're looking to Ryan White to suddenly begin to do what CDC is charged to do, and some others. I would hope that a part of what we would focus on is -- and I'm especially encouraging the idea that a big part of prevention -- and I love Hank's idea of putting a time frame on a goal which will talk about trying to eradicate this disease. Then we can talk about the kinds of things that we would want to put in place under the umbrella of Ryan White that would allow us to make sure that we're building the capacity that allows us to bring into the arena all the players that we need to effectively respond to the problem.

DR. O'NEILL: I've got to go.

I think that's absolutely correct, that the Ryan White CARE Act is not a prevention piece of legislation. It provides us with some levers and some ability to forward policy, and we're seriously looking at that. But we want to be careful and we want to be clear and crisp that this is a piece of legislation that has a particular focus, and we don't want to lose that, because if we lose that, we lose it at our peril.

It's also important to recognize that a tremendous amount of prevention gets done in the context of care, be that the nurse practitioner taking the time to talk to somebody about cigarette smoking or sexual behavior, all the way to fully integrated systems of care between CDC and state and HRSA-funded activities. It also includes thinking about substance abuse treatment, which is one of the most important things that we can do for HIV prevention. By the way, that's probably true globally.

So we want to be crisp and not burden. Dr. Parham's got those broad shoulder boards. She's

got broad shoulders, but she's got a lot to carry already without taking up that expectation that somehow this Act is going to also handle all the prevention issues. Other agencies and other departments have that responsibility. But it's the integration of this and looking for those synergies and those points where we really can find some of the creative solutions to these problems that we need to really challenge ourselves.

MS. THOMPSON: And I would just say I agree about the integration piece. Obviously, Ryan White is a $2.1 billion program, and CDC has its own prevention monies, over $700 million working on prevention, but really making sure that the two complement each other and that they're working in tandem to maximize those benefits. So if Ryan White is there to pick up as a payer of last resort, as a program that is looking to help low-income individuals, CDC and HRSA do need to be, as I think they have been, and maybe more so, really working in tandem to ensure that as people come in and touch the health care system, that we're able to get them into

testing, and if there's an unfortunate diagnosis of positive, that they're referred to the treatment piece, but to keep the prevention efforts obviously high and accelerated if necessary.

MS. SMITH: Thanks, Joe, for being here.

He said he'd try to get back in a little while, but we'll continue on with our discussion.

Cheryl?

MS. HALL: We've been talking a lot about testing, and I wondered if we could tie the testing to Ryan White funding. We want to make sure people are tested, and I'm not sure how we can tie that into Ryan White funding.

MS. THOMPSON: Tie testing to Ryan White funding?

MS. HALL: Yes.

MS. THOMPSON: There are prevention efforts that go on in Ryan White currently. But I think prevention is not just testing. I mean, prevention is a whole host of efforts, including behavior change and partner notification and testing. But in looking at prevention comprehensively,

obviously testing is going to be crucial. As we come up on National Testing Day, which is next Monday, that's sort of a focus right now in making sure that you know your status, which is a majority of the battle. I don't know if you can comment a little bit further. I'm not sure if I'm answering your question correctly.

MS. HALL: I think it's a bigger question. I think we'll have a discussion a little later on in terms of how we can really implement testing as part of treatment. But again, if we're into Ryan White, I'm just thinking you would have probably done your test by now.

DR. REZNIK: Sticking on the testing theme, and actually a comment I brought up at the last two meetings and yesterday, I work at a very large urban hospital, and we have a women's urgent care center, we have an urgent care center, we have an emergency room, and we don't offer rapid testing. Jackie Clements yesterday, who works at a Title III program, their state doesn't have enough money to buy tests. I did talk to someone from the CDC who says

the money goes to the states and the states disburse the money in the way that they see fit.

I wonder if there's a way that we can emphasize or require that a certain amount of the funds, or percentage of the funds goes to the purchase of one form or another of rapid testing - I'm not here to get one company - and also a way to sort of help break down some of the barriers that a public health hospital system might face in doing rapid testing. This is an old CDC initiative that was 10 years old at least, that the major urban hospitals, especially in the south now, would be a place where you would catch a lot of people who were falling out of care and that we could get them into care. So you have two examples. You have one of the largest public health hospitals in the country, and you have a Title III program in the south, and neither one of them are able to afford or put in rapid testing, and I think the direction, if it's a statewide direction, maybe some federal guidance can help us get more rapid testing into places where it's needed. Is there something that we can do in that realm?

MS. SMITH: Jackie?

MS. CLEMENTS: I appreciate your coming.

David, I will clarify that I work with a community health department, but it does have a Title III program. But I'm happy to see that prevention is being tied in with care, and I think it's very important in the sense that, myself being HIV-positive, I can say that people who are HIV-positive spread HIV. So we have to have prevention in care so that we can help people to understand how to live with this disease in a very responsible manner.

In terms of that also, we see that the disease is increasing sharply in the south, and the south is crying out for help in terms of care and in terms of prevention funding. So I hope that that will be addressed as we look into the future and in trying to eliminate this disease.

MS. SMITH: Dr. Primm?

DR. PRIMM: My concern, Carol, and I'm greatly concerned about this, is that there was a report out of North Carolina by Dr. Adamora from the University of North Carolina, who looked at three

counties up in the north part of the state where prisoners were discharged from prison back into those counties, and the incidence and prevalence of HIV became high. In New York City, where I come from, as you know, in Harlem alone, where a great number of people are discharged and come back from prison, one in every seven African American men are reported by the health commissioner as being infected with HIV.

I want something done specifically by this committee, some recommendations relative to what can happen in the prison system. Is there some relationship that we can have with the Bureau of Prisons, the Department of Justice, so that there can be some amelioration of this problem? Because it seeds our communities, and I'll bet you the same thing is happening all over the south and the southeastern United States. Mr. McKinnell talked about that a little earlier.

I think that unless we begin to focus this committee and the President's focus on that, it's going to be even worse than it is right now.

REVEREND SANDERS: Just a little footnote

to that. In the syphilis elimination initiative model, the five counties where we targeted to reduce numbers, one of the most important components in all of our initiatives was the jails and prisons. We were very effective in driving numbers down, and it had a lot to do with appreciating the fact that that was an opportunity to do education and testing. That was very important.

MS. SMITH: Monica, you're next. Oh, I'm sorry.

MS. THOMPSON: I agree with you, and we're definitely looking at the prison system and how that adversely affects the impact or the spread of the disease and how the federal government can more effectively -- I mean, obviously, some prisoners are incarcerated in a federal prison and some are in state prisons. But that's very much on the front burner of looking at the spread of the disease.

DR. PRIMM: My point is after the discharge, they come out, they cannot get Medicaid, so there's a break in their treatment even if they're on medication. We need to look at CMS to see can we give

them some way in order to be able to continue their medication so there's no break and so that they become more contagious, et cetera. I think that's most important, too.

DR. SWEENEY: I just wanted to follow up on something that Dr. Judson had mentioned earlier. In the Prevention Committee, we are trying to have an overall prevention plan coming out of this committee, and it is because the piper, he who pays the piper calls the tunes, it is a way to really forward policy, and there are lots of policies that we think could go a long way to reduce the epidemic if they were tied to funding, because people cannot afford not to have federal funding. So they would be brought into line with best practices, and states need to be given an adequate amount of time to come up to best practices.

But the funding should definitely be tied to best practices. Many times when we get data now for HIV and AIDS, we're getting it from 33 states. We should be able to get it from all 50 states because we all should have a uniform data system, name reporting, doing away with anonymous testing, testing all

pregnant women. There's a whole series of things that can be done that, if we do them, it will follow public health tried and true practices, and it will be a way of the federal government having great control over it if we can tie the money and the practices together.

MS. SHOEMAKER: Carol, I have a question. Would or could Ryan White be used as an avenue for saturating areas with the message of "Know Your Status," which combines in my eyes the type of behavior change and testing as one for taking the responsibility for yourself? Is that something that would be there, or would that be more in the realm of CDC or some other avenue?

MS. THOMPSON: Well, I think what we need to think about or have been thinking about is really not just looking at one avenue to get those kinds of messages out. I mean, I know that the private sector has been doing some things in trying to raise awareness, and I think raising awareness and understanding that HIV is not gone, there's still an epidemic, that we still need to address the issue, yes, through CDC, through Ryan White at HRSA, through

SAMHSA and the programs that they put out, and really throughout the Department, not only at a federal level but at a state level, so that people are really much more aware that they need to know their status regardless of whether they're part of the Ryan White program.

Obviously, Ryan White, if they reach out to 500,000 or 600,000 people, that's wonderful, but we do need to and we are hoping to really ramp up the awareness.

DR. YOGEV: With an increasing number of patients who are alive, in the last Ryan White one of the smallest parts was psychiatric and psychological services. Are you considering expanding that? Because the numbers are going to expand, especially if you connect it to prevention. Those services are not supported as well in the current Ryan White. Are there any thoughts of expanding it?

MS. THOMPSON: We're certainly working out the details, but obviously mental health and substance abuse treatment is key, I think, in so many aspects of either preventing the spread of the disease and

keeping it under control, anyone who is already HIV-positive. So absolutely, mental health and substance abuse are important parts of medical services.

DR. YOGEV: The unfortunate thing is they really are connected now, mental health and substance abuse, and I'm trying to suggest to separate them, because the substance abuse is part of the problem. Mental health is a much bigger part, and there's no funding for that because, at least in my state, they are connected, and you have now a whole population with a greater amount of mental issues not connected to substance abuse.

MS. SMITH: Karen, you're next.

MS. IVANTIC-DOUCETTE: Thanks, Carol.

A couple of thoughts, and hopefully I will bring them together in some way.

One of the things, at least in my review of the way Ryan White has kind of gone forward before, that I'd like to see removed is this notion of exceptionalism. We're trying to make HIV -- remove some of the exceptionalism around this in order to reduce stigma, and I think that the way the Ryan White

programs have been set up has encouraged some of that by targeting populations and things along those lines, and you're talking about wanting to integrate.

The other thought that we've been talking about is HIV you get on a personal level, and the treatment needs to be personal. Yet we're putting a public health approach onto some of these things. So when I hear integration, I think public health. When I think personal care and treatment, I think holistic, integrated on a much more personal level. So when I think about Ryan White and care and treatment on a personal level, we've been still doing too much of the public health piece of that.

So when you talk about testing, CDC has testing to targeted populations. But if we moved towards personal health in Ryan White where you integrate routine testing as wellness, we'll figure out how to pay for the testing if it becomes part of routine care in that personal perspective.

The other thing we know is one-to-one messages between providers and patients improves prevention activities, allows ongoing prevention,

those kinds of things. The notion of one-stop shopping, where primary care providers are providing the holistic care, which they're forced to do now, from HIV to gynecological care to mental health and substance abuse all within their particular focused visit, I think you would get better treatment, better prevention, and that notion of that kind of personal care.

The problem with the way Ryan White seems to me set up is that you still are fragmenting that on a provider level. If we could get better at funding central city practices, I think providers would want to do more of this. But the barriers under their productivity or reimbursement plans right now, they can't do it all, they can't come up to best practice, they can't spend the time that it takes, 45 minutes or an hour, on a patient in order to do all of those various needs. If there was a method to reimburse that instead of saying, okay, you're the payer of last resort, you need to go to this clinic for this, but you have to go over here in order to get your mental health or your gynecological over here or things along

those lines.

So on a provider standpoint, I think you have providers that would step up to the plate to do this if there was a method to allow easy reimbursement, higher reimbursement, within existing systems that allowed them to meet the productivity needs that they need to do in order to survive and provide a central city practice.

The other thing is the patient, removing the patient barriers to primary care, which means allowing me a certain amount of money so that I can provide bus tickets to some of my patients to come in, or pay for their dollar co-pay because I'm asking them to come in weekly to be seen. They can't come up with a dollar per week to be seen by a provider. So I think if you began to look at Ryan White as more of the personal integrated and used the system and then look at the public health a little differently, it just might be an interesting way to use dollars more effectively.

MS. THOMPSON: I'm not sure I completely understand. You're talking about having less

exceptionalism, so you're talking about people who go to their regular doctor that they're -- better trained, they're better reimbursed, that there's -- one-stop shopping as far as their comprehensive medical needs? I'm not sure --

MS. IVANTIC-DOUCETTE: I think it's a little bit of both. I think, first of all, having HIV is part of your routine, part of your ongoing screening for anybody that is in a care practice, but also scaling up the providers that are caring for patients or things along those lines, allowing whether it's a different reimbursement level, whether it's a different way to begin to allow that care and intervention to happen without segregating it out.

MS. THOMPSON: So you're talking about having more widespread capacity for providers throughout the country, that if their patient comes in and they find out that they're HIV, that there's more providers that are capable of taking care of HIV patients so that they're not --

MS. IVANTIC-DOUCETTE: I think it's multiple level. I think in a rural area you have to

have some primary care providers that are willing to step up to the plate. I find most primary care providers are not willing to step up because they don't have the time or the ability or the time to spend in the expertise. I think you still need to have partnership with infectious disease or HIV-skilled treaters. But right now, the bulk of the care is in primary care practices with limited amounts of time to deal with this number of issues. So what happens is the patients get lost, pieces of their care get lost, and, as a result, you aren't using your medical dollars very effectively.

MS. SMITH: Frank, you were next on the list.

DR. JUDSON: Actually, when I had my hand up, we were still talking about prisons.

(Laughter.)

DR. JUDSON: Which I think is a big issue that we have to continue to come back and address. I think where this group probably, and certainly I, lack the expertise and knowledge about how prisons are funded and managed at a detailed level, I think most

prisoners in America are in state and county prisons. I know Denver has a jail that takes people for 24 hours. That would be a good place for rapid testing. The county facility has people for an average, I think, of 30 or 35 days or so. The more serious crimes and the longer terms are largely at the state level. I don't think we have a federal prison that I know of in Colorado.

So it's going to come back to those issues of what the federal government controls and what the states control and pay for. Prison care is a huge, almost insurmountable budget demand right now in most states, but that's the challenge, what leverage we have on states, moral, financial, other ways to assure that nobody is released from prison without being tested for HIV and, if positive, there isn't some reasonable social follow-through to see that they don't just go back to becoming the source of a continuing epidemic. But I don't think you can do it from any federal jurisdiction that I know of would accomplish that. I don't know how much of state prison care is actually paid for by the feds. The

unfunded mandate is a big deal in most states.

MR. GROGAN: That's true, but we don't get the data from the federal prisons either. I mean, we've asked, and it's not there. So the state prisons are one issue, but we do have control over a lot of people who flow through the federal system, and there's no data. We've asked for it, and nobody in the private sector or CDC seems to have it. There's a rumor of a study coming out of Georgia, but that's the first thing I've heard about.

DR. JUDSON: Well, I'd suggest before the feds mandate that they take care of the federal system first, and then show the states how to do it after.

MS. THOMPSON: I will doublecheck, but I'm fairly certain that the federal prisons do test before departure, before release, and I think they refer. But you're right, there's some work to be done on the state and local level.

MS. SMITH: Ted, you're next.

DR. GREEN: Actually, when I had my hand up, I wanted to make a comment following on Dr. Sweeney's very reasonable sounding but radical

suggestion. What if we tied AIDS prevention funding to best practices? I would suggest not using best practices, especially in the international arena that I know best, but I suspect everywhere. Best practices has meant what we're already doing, what's popular. It's been based on consensus rather than some objective outside criteria.

So I would suggest what if we tied AIDS prevention funding to specific impact outcomes that are agreed upon in advance? Like yesterday, we had a presentation; there were two AIDS prevention ads that were deemed highly successful. So I said on the basis of what? Well, they raised awareness. Is that enough? If behavior change is important, and if one of the behaviors we're promoting is not engaging in casual multi-partner sex, wouldn't it be reasonable to tie AIDS prevention funding to those kinds of outcomes, surveys that show a decrease in the proportion of men and women reporting casual multi-partner sex?

So I think it's an important and a radical departure perhaps from what we've all been doing to

date to actually tie funding with the kinds of outcomes that are reasonable, maybe not at the level of HIV incidence and prevalence, because there are too many intervening variables, but if we're targeting behavior change, let's measure those behaviors and look for change. Thanks.

MS. SMITH: I apologize. I know it's difficult because you want to speak at the moment that a topic is underway, but we also have a number of people who have already asked to speak. So it's not a problem to go back to some of these issues again and again, because they're all important.

Reverend Sanders, you're next on my list.

REVEREND SANDERS: I'm going back to jails and prisons. I did fail to say when I spoke the first time that I wanted to say a public thank-you to Carol for when Carol and Claude Allen came to our meeting a couple of months ago. That was an especially high point for us, and I think that some of what you're hearing and some of our conversation and our effort is the by-product of that conversation. So I didn't want to miss the opportunity to say thank you for that.

Two things about jails and prisons, because we're dealing with two dynamics. One is that in one instance the jails and prisons represent an opportunity in terms of testing, okay? On another level, the jails and prisons represent a breeding ground, and the strategies are not necessarily the same in terms of how you deal with that. I think that Frank's point is especially significant in terms of point of entry, short term, and that kind of thing, I think testing -- and that's really what worked with syphilis elimination. It was more jails and prisons that I think allowed us to have some effect there.

But if you deal with it in terms of a breeding ground, it's very important for us to begin to move across departmental lines. We really need to be involved in conversation with the Justice Department as well, because then you have to deal with this whole issue of why our prison populations are growing. If indeed we focus on treatment within the arena of substance abuse over against the issue of incarceration, it does help us to cut off that stream into the breeding ground. Little things are

happening, and I was talking to Rosa about this earlier.

I want to applaud the State of Connecticut, which made a very brilliant move recently in terms of removing the disparity between cocaine sentencing. It's amazing how something that simple has an impact that's very significant upon us dealing with HIV and AIDS, because the mere fact that they will not have as many people flowing into their prison system means that the likelihood of the breeding ground continuing to grow and manifesting itself the way it does is going to be curtailed.

So it is important for us to begin, and if I'm not mistaken, one of the things that we have tried to do in the past is really talk about how across agencies we need to be able to have input and make suggestions that can have a tremendous impact upon this, because a lot of the prison problem could be addressed if indeed we made some adjustments in terms of policy with regard to sentencing over against incarceration.

MS. THOMPSON: I can do a lot. I don't

know about changing sentencing laws, but --

(Laughter.)

REVEREND SANDERS: I know, I understand. But speak to Justice, just holler over to Justice, say, hey, we need your help.

DR. JUDSON: Congress still writes the laws.

MS. SMITH: Hank is next on the list. If it seems like it takes a while to get to you, understand that you're here and it's in the order that people raised their hands.

DR. McKINNELL: I have a genetic predisposition to optimism, but there's a couple of things in the reauthorization of Ryan White that really worry me. One is that our basis for planning for the research we do is that those currently on therapy, 50 percent, will have failed all available therapies in the next five years. Now, I hope we're wrong. In fact, I think we might be wrong. But what that says to me is the plans you put in place today really have to account for a dramatic increase in the cost of treatment for those currently on therapy, and

we also need to make sure that those treated individuals have access to the medicines they need when they fail available therapies. So we ought to be very careful what we do here in our planning.

The second is I'm very concerned about the very high comorbidity of HIV and hepatitis C, and I think if we do our job we can make HIV a chronic disease, as are diabetes and high blood pressure and everything else we treat chronically, but there really are no good available therapies for hepatitis C. I don't see any on the time horizon that will help us where I think the problem is going to arise. We're looking at maybe a 20-year latency, and if you look at the populations that are alive today that became infected 20 years ago, that's a fairly small population today, but it's growing.

I think here, too, we're going to see quite a dramatic increase in the cost of providing care to those who are currently HIV-positive. So we could put in place a very good reauthorization that dealt with today, but we ought to be careful that it also deals with tomorrow.

DR. REZNIK: First, I want to second Hank's emphasis on people who are failing all existing therapies. That's something that I'm dealing with in my own home right now. There should be, not necessarily through Ryan White, but there should be some emphasis or some kind of reward for the companies who take the risk to develop new therapies. I do that for my personal and very selfish perspective, but I know that there are very many others in the country who are in the same position that I am, and it will be a global issue after a while.

I think one thing that hasn't been said is that the Ryan White CARE Act has done incredible things for thousands and thousands of people. It's been a very successful model of care. It's been a health care as opposed to a sick care model.

I also want to stress that this is an extremely complex disease. I had the honor of speaking at HRSA's International AIDS Society Clinical Care Update a few days ago in New Orleans with a tremendous group of people. I think I'm relatively smart, and I was coverwhelmed by the detail of what

people need to know about genetics and pharmacokinetics and all the different things that are now involved. I'm always somewhat concerned when I hear about mainstreaming this disease, because there's already evidence-based research that shows that people living with this disease who access providers with -- evidence-based, peer-reviewed published, excellent work that shows that people who are living with the disease who access providers who are experienced in providing this care -- I don't remember the exact number, over 50 or something like that -- had much better outcomes than those that didn't; that the level of knowledge that you need to keep up with, that I try to keep up with on a daily basis through some of the work of the AIDS education and training centers and some of the wonderful programs that are out there, it's really very complex.

I know we need to expand our reach to make sure that people in rural areas have access to this kind of care, but we need to make sure that it stays at an expert level.

Another point that I want to bring up is

that many of our existing treatment programs, such as the Infectious Disease Program, which I was so glad that you got to visit, that's my home; I'm there more than I'm at my home, actually -- that our providers are overwhelmed with the realities of what's going on today, that there are more people coming into care and people are living longer. So even though every part of our program, whether it's mental health and substance abuse, and I have to say oral health or I lose my oral health card -- oral health, primary care, our case managers and all the different people that we have in the program are involved in some degree in secondary prevention, our main job is providing care.

I'd like to see HRSA get some help from the CDC by integrating some of the CDC programs where you have your large or your Title III programs, where you know the patients are, and not expect the physician or the mid-level provider or the dental hygienist or the psychiatrist to do all of the work, but to have where the prevention expertise is and have them integrated in, because Ryan White, no matter what kind of changes come from the administration's

principles and the Congressional principles, is a relatively small program in the grand scheme of things, and we can only ask it to do so much.

So I'd ask that we do have to integrate treatment, care, and prevention. I always like working with my colleagues on the prevention side. But I think we also need to know that that expertise lies at the CDC. We also need to expand out those people who are able to do testing. There was a wonderful abstract published at the prevention conference by Jenny Cleland, who is a dentist at the CDC, and Lauren Patton, who is a dentist at UNC, showing that if dental health care workers were involved in testing, that we would bring in a significant number of new clients into the system of care.

So there are multiple ways of addressing a very complex issue. So to review, mainstreaming makes me nervous because we have evidence-based research showing that it doesn't work and that our programs are stretched, and that we need to keep that as a reality when we move forward.

MS. THOMPSON: One question. When you talk about that mainstreaming makes you nervous, how do you see HIV different than something else where if your primary care physician finds out that you're HIV-positive, or if your primary care physician finds out that something else is wrong with you, as you progress or as the condition requires, that you would be referred to more and more expert medical care? How does that differ then in your eyes as far as someone who is HIV-positive? That they would need immediately different care? I'm sorry. Am I being clear? No.

DR. REZNIK: Well, no, you might be clear, because the way the Atlanta EMA works is if you're asymptomatic, you haven't developed an AIDS-defining condition or illness, you are seen by our health departments, and no knock on our health departments but there's only a certain level of expertise that's there. As you progress with your disease, then you come to our program, where you do have this incredible level of expertise. So if it was just doing testing, diagnosing, and scaling a patient to see where they are as far as mainstreaming care, I'm for that. It's

once the disease becomes complex.

My mother -- bless my mother -- has to deal with me, and that's a whole lot to deal with. She has an internist and about 17 specialists. I am convinced she's at the doctor every other day. I normally call up with her to get her medical checks. She goes to specialty care because she needs specialty care, and HIV is such a complex disease that it requires specialty care on multiple levels. You have to have mental health specialty knowledge. You have to have substance abuse specialty knowledge. You have to have oral health specialty knowledge. You have to have primary care specialty knowledge.

So I think when you're talking about asymptomatics coming into care, hooking them up where they need to go, that kind of mainstreaming is fine because we want to reduce stigma. But because of the Ryan White CARE Act, there is a system of expertise that exists in this country that is unmatched anywhere in the world, and we need to make sure that we keep that intact and take advantage of the systems that do work.

MS. THOMPSON: So, Karen, how does that wash with what you're saying as far as --

MS. IVANTIC-DOUCETTE: I don't disagree as far as the expertise notion. If you have a low population, we need HIV experts and those kind of things. However, I think that most people aren't necessarily getting that, and some of the fragmentation in the way they can access, say in Wisconsin, we have a whole providers group that meets, all of the various groups that are providing HIV care. We meet on an ongoing basis. But the Medical College of Wisconsin, who has ID specialty, every patient has to have a primary care provider and a GYN provider and a substance abuse provider. They will only provide the specialty care. As a result, the GYN person puts a person on contraceptives not knowing that there's an interaction, and they end up pregnant because they didn't know the interaction of the medication.

So I just think that -- I'm not disregarding what you're saying. I'm thinking that primary care providers who are doing HIV expert work need to be given some kind of ability to scale up the

work that they're doing, meaning an easier way to get higher fees reimbursed, productivity time buy-out, so that they can integrate that care, not replace the experts. If I need somebody to see ID, I'm going to send them on to ID or to GYN. But I don't have time to integrate it in that practice. Does that make sense?

The other thing, too, just a note -- oh, I'm sorry. Just the other piece about that, because we've talked about transmission, there are increasing numbers of people that are transmitting drug resistance as primary HIV infection. So they're already resistant to many of the HIV medications, particularly in women. So I think the notion of doing ongoing prevention within our primary care practices is something that would be very useful. Does that make sense?

MS. THOMPSON: Yes.

MS. CLEMENTS: I'll be brief. We've been talking about testing here, and we've been talking about routine testing, we've been talking about rapid testing, and a lot of out folks are being seen in

community health centers, where routine or rapid testing can be difficult just because of cost. The cost of the test runs $13 to $15 per test. Is there any conversation with the Bureau of Community Health Centers getting them into the conversation and the funding stream so that some more testing, routine or rapid testing, can be done at that level?

MS. THOMPSON: The short answer is yes. The community health centers and the President have put forth an initiative to expand community health centers greatly. So we're certainly looking at and working with HRSA and the folks that are primarily responsible for community health centers and looking at how best to integrate with not only existing but the incoming and new community health centers that are coming up, because obviously they're going to be reaching populations that may not normally have access to something like that.

MS. SMITH: Mildred?

MS. FREEMAN: I wanted to support what Dr. Primm was saying about making care available for inmates returning into the population. I find it

alarming that 70 percent of the new cases are in the south. I'm alarmed that the HBCUs are located in only 24 states in the country, and most of them are all in the south. I think that if we provide this care immediately where the epidemic is disproportionately affected, especially by minority women, Afro-American women, we cannot wait for a national policy when the outbreak right now seems to be concentrated in the south.

So I wholeheartedly support that you include in continued care for inmates returning to the general population as one thing that we can do to sort of stop the spread of this epidemic to people of color in the south.

MS. SMITH: Lisa?

MS. SHOEMAKER: Well, as a person living with AIDS in a rural area, I just want to reinforce what both Karen and David said. Ryan White I think could take the stigma away and have HIV become more generalized into the mainstream, but also utilizing our specialists.

What happened to me just recently was our

care specialists are two hours away. I have one that's 30 minutes within my reach and one that's two hours from me. So depending on who is listening to me, that's where I would go. Karen helped me out in just these last couple of months when they reassigned me a general practitioner or primary care doctor, because they really don't know what to do with me because I'm not going into the AIDS mode. I'm now getting older and going into the old folks mode and having all the stuff happening that's happening there, but they didn't know what to do with me with all the other ailments because it's not pertaining to the HIV/AIDS.

What we've been finding -- I'm also a motivational speaker/teacher, and I go in and teach the kids, and they're coming away with more information about HIV/AIDS than most of our generalized doctors. This is what's scary to me because they have more knowledge, and I say go tell your siblings and your friends and your grandma and grandpa, and they freak out when they find out that grandma and grandpa still do it. But they're going

and becoming teachers, whereas the doctors, they don't want to touch anything, and this is the problem we have because in the rural areas everybody is exhausted who is in the HIV/AIDS fight.

We've got, like I said, two caregivers within two hours of each other. But what happens to everybody in between? The doctor that I have now is a gem. I feel he listens to me more than even my specialist did. I'm getting my needs met. He double-checks all the medication that I'm taking, which we had at the Thomas Judd Care Center. We had a pharmacist and a counselor, but all of that slowly has been dying out because the money hasn't been there. So now it looks like everybody else is going to have to take up the slack. I'm saying we need to teach our doctors, no matter who they are, that they have to recognize HIV and AIDS, and they have to accept it and deal with it, and appropriately send you on to who you need to see, whether it be them or somebody else.

But it's got to be something that's generalized across the board. It just can't be from state to state. It's got to be every state.

Everybody's got to be on board.

MS. SMITH: Dr. Primm?

DR. PRIMM: We were talking about collaboration and cooperation particularly among governmental organizations, and I cannot help but think about SAMHSA, Substance Abuse and Mental Health Service Administration. And in that agency that the prevention efforts or the testing efforts for using the rapid test is in the Center for Substance Abuse Prevention, which is the lead agency in that agency. I think it ought to be across all of those agencies, the Center for Mental Health Services, and also the Center for Substance Abuse Treatment as well.

All of them have an opportunity to do testing. Instead of it just coming out of one particular agency within that agency, I think also that the Center for Substance Abuse Treatment, when I was in charge of that center, I had a program with prisons, with the Bureau of Prisons and the Department of Justice where I actually had monies to go into the prison system and set up drug treatment programs where people would have a continuity, if they were drug

users, from when they went into prison, they'd come right out and go right into another drug treatment program that was aligned with that prison, whatever that was.

So I think it's really important to have these bridges so that there's a continuum of services. Plus, we can start to test, we can start to treat, and then both substance abuse and the HIV treatment in the prison system, and to begin to recognize what is the hepatitis C problem. In my own patient population in New York where I run drug treatment programs, I have 3,000 patients. Eighty percent of those 3,000 patients are hepatitis C positive. So we're talking about a serious issue here if we don't focus on all these things and begin where we can catch them early, and that is in the prison system, very early in the jails and prisons. It's most important.

And to insist from your perch that what happens in SAMHSA is across the board and that there is communication between SAMHSA programs and the BOP, Bureau of Prisons, and the Department of Justice. I mean, that has to happen. You can knock those heads

together and make that happen.

MS. THOMPSON: I appreciate that. I do think you're right. I mean, obviously, working with prisoners, especially as they approach a release date and they come back into the society and into the system, you're right, the continuity of care is important. That seems like an obvious sort of turning point or break point for us to be able to tackle their health situation so that they don't continue to spread the disease. I agree.

MS. SMITH: Rosa?

MS. BIAGGI: I think that this has been a rather hard to follow session because of this back and forth between Ryan White and prevention, and I think that speaks to the confusion that the community will have as we try to integrate care and prevention. There's a lot of players here, and that comes from the top. I mean, we have CDC, we have HRSA, we have SAMHSA, and then we have in the community the same thing.

I'm going to speak mainly around prevention programs, because the sentiment I hear

around the table is that confusion about the CDC allocating funding to the states and the states doing whatever they want to do. As director of the AIDS programs in Connecticut, I need to clarify that point because the CDC does provide guidance on what to do with the funding, and we have several mandates.

One of them is following the recommendations coming from the CPG, the Community Planning Group, so that whatever the planning group puts together for priority populations and priority interventions, it is done because that's a mandate of the CDC that we follow the recommendations of the Community Planning Group. So indirectly, whatever is being implemented at the state level is because the CDC is allowing that to happen.

The state, in communication and coordination with that community, prepares these plans for prevention. On the other hand, the CDC has been encouraging -- and this is like a dichotomy here. We have about two years ago, when we had the advancing of HIV prevention initiatives, there were four core elements included there. However, the CDC funded

several across the nation, AIDS services organizations to implement these new initiatives, and they were really, really mandated to follow the advancing HIV prevention initiative.

Now, for the jurisdictions, for the states and other jurisdictions, what we have now, what the states receive is basically just that the CDC is promoting the implementation of the DEBIs. Those are the Diffusion of Effective Behavioral Interventions. It is not mandated. It's just a promotion. The CDC is saying, well, we go better with doing away with just the distribution of pamphlets or condoms and not having a long-term prevention intervention that could probably result in a very positive outcome in terms of behavioral change. So they are really encouraging states to implement the DEBIs.

That is what's up to the states to decide, whether they want to go with that or not, because it's not a mandate yet. In Connecticut, I'm very proud to say that we just conducted a competitive process for HIV prevention funding, and under my management we decided that we are not funding any program that is

not part of a DEBI. So we're not doing any outreach just for outreach or distributing condoms just for the sake of distributing condoms. We are just purchasing services from organizations that are implementing the DEBIs, or at least programs that have a procedural guidance.

But again, not every state is doing that, and that's where we have states still doing what has been done for many, many years, in some instances very effective but hard to prove. So if anything, if we really want to see these effective behavioral interventions being implemented across the board with possibly better results for HIV prevention, it has to come mandated by the CDC directly, because otherwise you have the states drawn to fund other programs that are not following the epidemic. So I would encourage the CDC to look into mandating the implementation of the DEBIs with every single dollar that they put out there for the jurisdictions.

In terms of the integration of care and prevention, definitely it has to come also from the top. My experience is from all the federal agencies,

the only one that is really looking, from what I see, at a very comprehensive spectrum of services, is SAMHSA. They are even incorporating the HIV testing, using rapid testing and mental health services and substance abuse. They're really looking at that. When you look at the CDC, you look at testing and DEBIs. When you look at HRSA, you look at care, care, care. Everything is good, but not one federal agency is really looking at a comprehensive approach to this, and that is translating into what's happening at the state and local level, a great fragmentation of services that needs to be corrected from the top.

Thanks.

MS. THOMPSON: One thing I wanted to pick up on Dr. McKinnell's comment about looking at the future. Obviously, you're sort of worried about the next hour, the next day, the next week, what's going to happen by the end of the summer, when is Ryan White going to be reauthorized. But I'd be interested to know what are your thoughts not only on -- I mean, we've been talking about prevention as it relates to HIV, but what are your thoughts on really a bigger or

a grander scheme of looking at eradicating, eliminating, reducing extensively HIV from the United States and hopefully from the rest of the world?

DR. JUDSON: That's the very question that we posed to ourselves in the prevention group and that I hope our paper responds to or answers. We began with the reality, which is that although the CDC has had a kind of pull out of the air goal of reducing HIV infection incident cases by 50 percent by, actually, this year, here we are. So rather than being reduced by 50 percent, if anything there's been a slippage in the other direction.

So we started off by saying whatever we're doing, it isn't working or it isn't taking us beyond an unacceptable status quo that will add 20,000 to 30,000 new HIV patients or add to the rolls of those living with HIV, 20,000 to 30,000 patients per year. So we did go back and consider everything from advertising, counter-advertising, public health laws, criminal laws, reporting, incentives and disincentives for how federal monies are spent.

One of the realities now is that as you

move towards an entitlement, if that's where things happen to be going for HIV, to me, by the way, I think that's a disaster, because I think the public at some point, the much larger taxpaying public is going to say why HIV and not all these other infections that weren't even caused by elective behavior? To go back and say do we want to continue to have almost an open door entitlement system where we continue to pile on treatment benefits, like hepatitis C, and where the more patients you have, the more money you get? There needs to be some way to realign those incentives and disincentives.

For individuals, the disincentives should certainly outweigh the incentives for getting HIV or becoming exposed to HIV. For providers, the incentives for keeping people on treatment and for learning their potential source of infection and preventing potential subsequent spread, there should be incentives to spend time to do that. Of course, at the state level, the incentives really must be there to see that they know who within their state is at risk for getting HIV now, not 10 years ago, and who

the new infections are, and that they develop a living prevention plan to adjust to those changes in epidemiology and bring to bear prevention resources.

DR. SWEENEY: Carol, Frank has gone over a lot of what we did in the Prevention Subcommittee meeting. I'm not going to read our two-page draft to you, but I will ask Anita if it's okay if we make it available to you. But we've gone over many of the issues from policy changes nationally to responsibilities that we think should be state and local law, to federal responsibility in terms of moving policies in a certain direction. It is just a draft, but I would be happy to make it available to you, because we want to get all of the elephants out of the room. That's Hank's word for it, an elephant in the room.

We have addressed a lot of the elephants, and we hope before today is over we will have had time to address any more that our fellow Council members have around the table and look at public health law in its fullest and how it can be brought to bear to help change what has not been successful. So we'll get you

a copy of it.

MS. THOMPSON: Great.

DR. McILHANEY: Carol, I think, just to sum it up, for me, there's been one concept that's been talked about here more than at any other time, and it's really, really exciting to me. That is that the word "eradication" or "elimination" of HIV has been used a lot around these tables the past two days. Though it's been mentioned in the past, primarily in the past we've talked about prevention and so forth, but we really hadn't talked about eradication or elimination before this much. So I think that if you combine all of our thoughts about it, including these that Monica is talking about, that you'd find that that probably is becoming our goal.

MS. THOMPSON: Great.

MS. SMITH: Cheryl?

MS. HALL: Carol, I just wanted to go back to something you alluded to earlier. The President's initiative to increase health centers throughout the country does not offer separate funding for rapid testing. I think at the present time, if you offer

it, you have to absorb the cost. So at our sites we're offering it free, but we're absorbing that cost, and it's to anyone walking into the health centers or, obviously, if you got to the delivery room without getting a test. So I wasn't sure if you were saying that this cost would now be covered in his initiative or if you're saying that there's a separate line in the new Ryan White funding for this. Can you clarify?

MS. THOMPSON: No, I did not mean to say that every new community health center was going to be equipped with that, but we're certainly headed towards circumstances, as we were talking about availability and mainstreaming and having people so that folks that community health centers are their closest and primary opportunity for any kind of health care, that we'd certainly like to see more and more that the ability to test, the ability to counsel, if a person needs to be referred, that that's more and more in the plans of what's going on.

MS. HALL: It's really certainly a great opportunity, and I think we should follow through on that with all the health centers that the President's

initiative is going to add for the access points.

DR. YOGEV: To your question about the future, it's probably not in Ryan White, but the solution to this infection is a vaccine, and there must be major efforts through NIH and incentives to industry to produce one. There is no disease that we're able to conquer by changing human behavior. Look at the efforts at pregnancy, which is somewhere into that effort, the HIV we're talking about. I'm very much in favor of everything that was said, but that's a definite.

One thing just before that my two colleagues were trying to express. What we found ou -- and the Ryan White is a little bit against it as it stands now -- is center of expertise that work with the physician. I'll give an example that I'm familiar with. We saw -- for example with a psychologist and a specialist in HIV and social worker, whatever, and then sent patients to the community and connected to the physician in such a way that we come to him, he comes to us, or she, and distances even up to 300 or 400 miles away, that they look after the patient, we

do the expertise part, and let me give you an example why HIV is different.

In syphilis, you have somewhere around 15 different antibiotics you can give. In HIV, you do two mistakes and you're finished, basically. You have to start from the beginning the right way, and that's why 50 percent of the patients fail within one year with their therapy, because of this notion, and we already have a problem with them. Ryan White is separated. Some people go to one place, some people go to another one, and you need to consider encouraging center expertise that have to share with others, not to become the center, the ivory tower, but the one which relates.

Wisconsin has such a thing for children. There is one in Milwaukee who is taking care of all the southern part of Wisconsin. Their physicians pick up and send every three months, six months, it depends, just for a tune-up.

MS. SMITH: I'd like to ask if anyone, Karen or David, has something to speak on behalf of your two committees to answer Carol's question related

to what we were discussing about how we move forward in terms of the epidemic. I know that the International Committee has an outline, as well as the Prevention Committee, in terms of discussion that was based on that premise, and I don't know if, David, you have something from the Treatment and Care related to that.

DR. REZNIK: You mean for long term?

MS. SMITH: Long term, right.

DR. REZNIK: That was actually going to be our lunchtime conversation today because we met prior to that. But I beg the chair's patience to make one more comment, if that's okay with you.

MS. SMITH: That's fine. I'm just trying to get some answers to Carol's question.

DR. REZNIK: Well, we know we can't treat our way out of this disease, but treatment is an important way of making sure that the disease stays under control. I'm bothered by the word "entitlement" that was used. It was in a document I saw earlier, and then, gratefully, it was no longer there, but it came up today.

There was this wise lady, a patient of mine in 1988 -- and once you're in my chair you're scared to death -- an African American lady, administrator at our hospital, who said, David, you know, one day there is going to be a problem, and the problem is going to be that the disease isn't going to look like you any longer, it's going to look like me. She was very wise.

I've always been concerned that when the disease shifted from a group that we heard this morning had some kind of political clout and power and then started addressing others that may not be quite as empowered, that words like "entitlement" would come into play and that the systems of care that I find to be so exceptional, because I think Ryan White takes care of at least 70 percent of our patients, I think, are African American, and I don't want there to be any kind of dilution because it's not affecting gay white males that are empowered, such as myself, and are infecting those that I come here trying to represent, which is my patient population, who have significant comorbidity factors, who are dealing with levels of

discrimination I never could understand.

I'm the child, as I told Dr. McIlhaney as we were walking yesterday, of a holocaust survivor, someone who knows discrimination. But I can look German, I can look a certain way. So I have a concern that those core services that are vital to keeping people healthy, which is important to eliminating this disease, stay in place during our five-year plan, our 10-year plan, that our prevention activities and our testing activities get to the point where we do see a reduction and that people will be living longer until Dr. McKinnell and his colleagues and our people at NIH come up with a cure for this disease, and not try to pinhole it.

MS. SMITH: Rosa had a comment I think in response, and then Karen.

MR. GROGAN: I promised Carol that I'd have her out of here at noon, and we're two minutes from there. So if we can wrap this up.

MS. SMITH: So very short.

MS. BIAGGI: My comment is very short, and it's around the Ryan White reauthorization. One of

the things that we have now is the ADAP crisis, and that is experienced almost across the nation. Some states have been spared from that, including mine, because of the connection we have with the Medicaid program and the ability for us to participate in the rebate from the pharmaceuticals. That's helping a lot.

However, one of the things that I see as part of the crisis is not just the money. It's also the use of the money. The ADAP for purchasing medication is a great thing that we have. I would recommend -- this is from the experience of Connecticut and other states -- more emphasis on supporting treatment adherence, not just medication adherence but the treatment adherence. I always wondered what is the good of purchasing the medications if we don't have the ability of the clients to follow through their treatment. It's very complicated. Many of our clients have cognitive issues that will impair their ability to follow through their treatment.

So we're putting the money there for purchasing the medications, but we are not putting

emphasis on medication or treatment adherence programs. So I would recommend to take the opportunity of the reauthorization of the CARE Act and look into the option or possibility of mandating the use of portions, whatever percentage we want to name, to be used for supporting medication adherence programs for every state that receives ADAP for medications.

Thanks.

MS. SMITH: I think Karen will have the last word at this point.

DR. McKINNELL: Can I just support that? Will you yield? I'd just like to support that very important comment, because the data is very clear that if a patient on therapy misses one or two doses per month, they start to lose effectiveness. If they miss 10 doses per month, they might as well not take the drug. Rather a sobering thought.

MS. IVANTIC-DOUCETTE: Well, on behalf of the International Committee, first of all I'd like to thank you, Carol, because one of your opening comments was about the U.S. having some kind of modeling to the

rest of the world. So those are some of the comments that the International Committee has been thinking about, or concepts. Key for your thinking might be, again, that notion of we're looking beyond an emergency plan. Right now we're in an emergency plan. Ryan White certainly needs to go to the next phase. But are we ready for a forever plan? That notion of entitlement, where are we in the process. So that's some of the thinking.

We cannot be in an emergency mode forever, that the plan that is developed needs to be marketed. We are the marketing of the U.S. plan, and we think that it needs to be coherent and effective so that there's impact in what we do in Ryan White on the international PEPFAR players. Collaboration has been a key point all along, the notion that one size does not fit all in both plans.

The notion of developing stretch goals, the AIDS-free generation and HIV-free generation, eradicating HIV throughout the world. Goals drive behavior and open up new thought processes. So those were some of the key things, realistic obtainable

goals need to flow from the stretch goals, and that the U.S. really does need a road map for that.

So I think those were some of the key points from the International Committee, and we thank you for maybe providing that road map.

MS. THOMPSON: Well, I appreciate everyone's comments and time today. I have taken copious notes, and I understand we might have something transcribed as well. But obviously, as we've discussed before, you all are out on a day-to-day basis interacting and seeing how the plan, the program, the CARE Act is put into practice with patients every day. But I do agree that sort of a long term and bigger thinking is important.

Obviously, as we're looking at Ryan White, which is a very important piece, but one piece of the federal government's response to HIV and caring for those that are HIV-positive in the United States. So we're certainly working and doing our best to come up with changes in the reauthorization that will really hit those in greatest need throughout the country.

I appreciate this, and we'll certainly

look forward to future conversations.

MS. SMITH: Thank you so much, Carol. We appreciate your being here. It's a lot of time for you to give us, and we're pleased if you have other questions that you'd like our response to, you can get them to Joe in writing and we can try to respond to those as well. Thanks so much.

(Applause.)

MS. SMITH: Now we will break for lunch. Joe can give us instructions.

MR. GROGAN: Yes, we're going to break for lunch, and instead of going into our subcommittee separate rooms, we'll reconvene here in this room at 12:30. They're going to bring in lunch right now, but we'll start up again at 12:30.

For members of the public, there's a cafeteria across on the other side of the elevators.

(Whereupon, at 12:06 p.m., the meeting was recessed for lunch, to reconvene at 12:30 p.m.)

A-F-T-E-R-N-O-O-N S-E-S-S-I-O-N

(12:55 p.m.)

MS. SMITH: I think we'll try to start our discussion here, if we can focus on our motions. Others who have later flights might be able to change them and get home a little earlier.

In this section of our meeting, what we're going to do is consider first two motions from the International Committee that Karen will be introducing, representing the International Committee in Abner's absence today; and then we will move to a discussion of the Prevention Committee's outline. Then we also have had an International Committee outline that's been distributed that we'll be talking about.

I just wanted to mention before we get into this discussion that the next few months will be working very hard in each committee to prepare some documents that will be geared to the November meeting. I wanted to just alert all of you to the importance of your attention. When you start receiving some emails with information that we're asking you to

review in preparation for our next meeting, please take the time to do that and to respond and respond thoughtfully, and we'll be moving together as a council as we work individually in the committees and within the PACHA office.

You'll be hearing more about some of the timetables and things that you can be expecting from your committee chairs. Joe and I and Dr. Sullivan will be working with the committee chairs on the different documents that we're preparing for November. So I thank you in advance for your attention to these issues and your feedback, because that will be very important as we move forward.

Cheryl, you had a comment?

MS. HALL: Just a question. Do we have a quorum to pass any of these resolutions?

MS. SMITH: I believe so.

MR. GROGAN: Yes.

MS. SMITH: Yes, we do have a quorum.

So we will consider the two motions that are being put forward by the International Committee, and they're both in front of you. Karen, if you would

be so kind as to go through them with us.

MS. IVANTIC-DOUCETTE: Well, thank you, Anita, and thank you, Council members. I'm filling in for Abner today, who I'm sure would do a much better job here.

The first resolution that the International Committee would like to put forward is the resolution to eliminate taxes and tariffs on donated medical tests and other materials used in the diagnosis and treatment of HIV diseases. This is the resolution that we had that Mr. Bates spoke to yesterday.

Do I need to read it into the record?

MS. SMITH: No. We simply have to have a motion to approve, and then we can have discussion, and a motion second.

PARTICIPANT: So moved.

PARTICIPANT: Second.

MS. IVANTIC-DOUCETTE: Is there discussion?

DR. McKINNELL: One that's kind of editing. In the second line, I would talk about

provision of drugs, tests and other materials to make it consistent with the bottom. It's just editing. We added "tests" here. We didn't up here.

MS. IVANTIC-DOUCETTE: Okay.

DR. McKINNELL: And the second one is when drugs are provided at reduced prices, free, or at cost, that sort of says the manufacturer has done their part, and the government needs to do their part, which means not tax it. But I wonder if we couldn't go a step further and make it applicable to all medicines for HIV testing and treatment. Why just those that are provided at concessionary prices?

MS. IVANTIC-DOUCETTE: So how would you edit that?

DR. McKINNELL: Well, in the resolution, it applies to free, reduced price or donor funded medications. I guess donor funded would cover it. If donor funded means anything used in compassionate use or non-commercial use, I would say that's fine. I suppose that's clear.

MS. IVANTIC-DOUCETTE: So leave it.

DR. McKINNELL: Well, I don't know what

people think.

MS. IVANTIC-DOUCETTE: Monica? And then Frank.

DR. JUDSON: Did we answer Frank's question or prepare a proposal?

MS. IVANTIC-DOUCETTE: I think he answered it himself. Is that correct?

DR. McKINNELL: Yes.

DR. SWEENEY: My question has to do with the fact that, again, it's AIDS exceptionalism. What about tuberculosis and malaria and other things? Why are the medicines for HIV only being singled out?

DR. JUDSON: I would answer that, that if we're thinking PEPFAR, because that's really what PEPFAR is, and it keeps it clean and connected and understandable. I would think that the Global Fund for HIV, TB, and Malaria would do that, and I would think that any other international group, Gates or whatever, who is donating medicines, would not accept them being tariffed or otherwise taxed.

DR. SWEENEY: Then I think we should say it.

MS. IVANTIC-DOUCETTE: We did deal with that in terms of we included medication. We took out the ARV provision, the HIV provision, because tuberculosis drugs and malaria drugs are most likely used internationally in HIV treatment, so we thought that that would be broadened. But again to Frank's point, the thinking was keep it clean, because you don't want it to be open to too many things.

DR. JUDSON: And you don't want to give them an excuse, the governments in some of these countries, to say that you're arrogant, you've gone way beyond your mission, and that we maintain some control over our taxing policies.

MS. IVANTIC-DOUCETTE: Does that answer it, Monica?

DR. SWEENEY: But PEPFAR is for HIV, tuberculosis and malaria. My point is at least we should be inclusive enough to include those disease states that we are addressing in PEPFAR.

DR. JUDSON: It's only through the Global Fund that it becomes TB and malaria as well, right? Or has something changed?

PARTICIPANT: I think that is right, and not malaria outside the Global Fund.

MS. SMITH: It depends on the country you're working in. In some of the countries, the U.S. government team is requiring you to work on malaria if you're doing PEPFAR because they have certain programs they want everyone to participate in.

DR. JUDSON: So aside from the Global Fund, the 16 targeted countries, some of them have --

MS. SMITH: Not officially. But when you're working in that country, you sometimes are required to do things on malaria or TB.

MS. IVANTIC-DOUCETTE: Abner was the one that drafted this. But for the International Committee, would we accept as an amendment to this the treatment of HIV, malaria and tuberculosis?

MR. GROGAN: It's one of the things to consider, but we are the Advisory Council on HIV and AIDS. So to what extent are we getting out of our purview by talking about other diseases that may be part of other administration efforts but aren't necessarily our issue?

MS. IVANTIC-DOUCETTE: So stick to HIV? Okay.

DR. GREEN: And also the price of ARVs is exceptionally high and is higher than other drugs.

MS. IVANTIC-DOUCETTE: Well, this is a beginning, and you know that the other diseases will follow suit, or at least you hope that that expectation will be there.

Any other further discussion?

DR. YOGEV: Should we add at the bottom the consideration to other medications should be given so we don't say it but we encourage it?

DR. JUDSON: I don't think so myself. I think that these are essential AIDS drugs and we should keep it real clean and simple at this point.

MS. IVANTIC-DOUCETTE: Which it is at this point.

DR. McILHANEY: I just have a question. It makes me feel like I'm walking into the surf and don't know when it might drop off. Is there anything that I don't understand about taxes and tariffs and stuff that would affect this, or is this pretty clean

and simple to do this?

MS. IVANTIC-DOUCETTE: It's very simple. The only thing that we want is we want the elimination of the taxes and tariffs on medications that are currently somewhere in the range of anywhere from 16 to 38 percent on all the medications coming in.

DR. McILHANEY: To me, it's a "duh, of course." I mean, I think it's a great idea.

MS. IVANTIC-DOUCETTE: Thank you for your comments on that.

Any further discussion?

(No response.)

MS. IVANTIC-DOUCETTE: Can we call for a vote? All in favor?

(Show of hands.)

MS. IVANTIC-DOUCETTE: Any against?

(No response.)

MS. IVANTIC-DOUCETTE: Any abstain?

(No response.)

MS. IVANTIC-DOUCETTE: The resolution passes unanimously. Thank you.

The second resolution you have in front of

you, it still looks like it's in draft format. We will resubmit that. But it calls for ensuring broader programs of AIDS prevention in implementing the President's emergency plan for AIDS relief. We'd like to introduce that as a motion. Would someone like to introduce that?

PARTICIPANT: So moved.

PARTICIPANT: Second.

MS. IVANTIC-DOUCETTE: And I'd like to have Ted and Ram take the lead on explaining this. Any questions? It's open for discussion.

DR. YOGEV: It's just in a draft form, but this is the final. Unfortunately, we gave it to Joseph at 5:30 yesterday afternoon. But the way it's written with the one correction, that's the resolution.

MS. IVANTIC-DOUCETTE: Do you want to spend any time explaining why this resolution is coming forward at this time?

DR. GREEN: I can make a little comment, yes. We had a so-called ABC resolution last year or a year and a half ago, whenever it was, and basically

after PEPFAR -- well, first USAID adopted the ABC approach to prevention for generalized epidemics. That was in late '02. Then in late '03, the PEPFAR legislation and policy documents also adopted the ABC approach to generalized epidemics. All we said in that first resolution was we support the policy. Well, that was not doing very much. We ought to support the policy of our President and administration and PEPFAR and so forth.

This one recognizes that it has not been a seamless process of implementation, that a lot of rank and file people working in developing countries aren't really comfortable with this. They're used to doing AIDS prevention the way it was done prior to the ABC adoption. So this recognizes that all the elements of the ABC policy are not being implemented. So all this does is select the impact indicators. All PEPFAR-funded programs are supposed to have a monitoring and evaluation component, and there are also impact indicators that have been worked on by USAIDS and UNAIDS and various organizations. So there's a group of impact indicators that PEPFAR has adopted, and they

relate to stigma reduction and condom promotion, a number of things, discrimination, mother to child transmission, just to know that we're having some impact, we're achieving our goals.

So the ones that relate to A, B and C, the basic ones are here, and what this motion says is that unless there's some exceptional reason, such as there's a project design that only targets commercial sex workers or only targets youth in primary school, so that by design the first one would not have an abstinence component, and the second example of the primary school children would maybe only have an AB component, abstinence and being faithful. There have been two rounds of PEPFAR-funded programs that are called AB programs.

But other things being equal, unless there's an exceptional reason having to do with a specific target group, a target audience, or a project design, then all three of these elements should be in a prevention program, and these are the basic indicators.

MS. IVANTIC-DOUCETTE: Questions?

Hank, then Monica.

DR. McKINNELL: I thought last night about our general discussion yesterday and a couple of side discussions we had with my allied doctor, McIlhaney, and it seems to me that to the ABC we need to add three AAAs, which is appropriate messages to appropriate groups at the appropriate time. If I could stretch to add a fourth A, it would be and exclude no one. I think that kind of captures where I think most of us are, that we know condom-only programs don't work, I think it's clear abstinence-only programs won't work, but if we could draft a strategy that included all three of ABC, and then added appropriate messages to appropriate groups at the appropriate time and exclude no one, then I think we've got a comprehensive strategy.

DR. SWEENEY: I like your A cubed program. One question that I wanted to know is why the age in B was 15 to 49, when so much intergenerational sex takes place, especially between older men and younger girls? By putting 49 on it, you exclude a very large number of people who are sexually active. I think

that that should not be the case.

MS. IVANTIC-DOUCETTE: Would you suggest just eliminating the age there? Why couldn't you have the percentage of women and men who have sex with more than one partner in the last 12 months?

DR. SWEENEY: Right. I would just eliminate the age.

DR. GREEN: Actually, I want to point out that these are from the list of suggested PEPFAR indicators. You raise a good point, and I think a lot of us would agree that we should start measuring and targeting younger youth, maybe starting at the age of 12 rather than the age of 15. But these are decisions that have been made by PEPFAR, and these are the indicators, and those are the groups that are being primarily targeted. So I think we use the ones that already exist. If we want to change those, maybe we could think about doing that.

DR. SWEENEY: I just wanted to say if we did the A cubed also, it would also say exclude no one. I think by saying 15 to 49, we're excluding a lot of people. So I don't know, because these are

already the PEPFAR indicators, how you would want to handle that.

Just my last comment is, because we've had people talking about abstinence only and other people talking about condoms only, I was giving a talk not long ago and there was a former Surgeon General there who was commenting on my book. Somebody had asked a question to me during that talk about condoms breaking, and afterwards I was told your answer was good, but what you should have said is yes, condoms break, but not nearly as often as vows of abstinence.

DR. JUDSON: My own opinion on the 15 to 49 is that we probably don't want to be changing just for consistency sake, for clarity sake, established terms. So I would agree with you that people are having sex under 15 and over 49, but if that's the way it's established right now in PEPFAR, unless it's a huge problem, we should probably leave it that way so it continues to communicate consistently.

The other thing is on the appropriate, I tend to, when I edit things down, I'm always looking for simpler, shorter ways to say things, and

"appropriate" is one of the words that I strike out most often in medical writing and communicating because it just has a subjective quality to it. For some people, condoms may be appropriate for all persons in all situations, and for others they're never appropriate, maybe the Catholic Church.

MS. IVANTIC-DOUCETTE: I'm going to ask Ram to answer that question, and then we also have Joe and Lisa that have some questions, and David, and then Ted, you also want to, and Reverend Sanders.

DR. YOGEV: Frank, I agree with you, and want to disagree on the other one. You're right that, for bureaucratic reasons, it would be nice to keep the 15 to 49. But being aware that one of the traditions in some countries in Africa, if you want to get rid of AIDS, you sleep with a virgin which is less than 15. That's where you get your data. We need to put a standard and not to follow it, and I would highly encourage to put any age and take the age out completely.

I agree with you on appropriate, and we had a big fight yesterday because you put "equal," and

the word "equal" is even more dangerous in a certain way because then you become too rigid. I thought the solution is three times appropriate, which is subject to becoming bigger, which is what you suggested before. Instead of the word "equal," as you can see, we put the word "appropriate" in one place and leave it there instead of going on and on and on, that if it's not appropriate in time, not appropriate in age, and really pushed the issue that you need to take all three as much as you can, and you need to tell us specifically why not and not the other way around.

DR. JUDSON: Well, it's also how far you go with a resolution.

MS. IVANTIC-DOUCETTE: Let me just ask this question about --

DR. YOGEV: It's an appropriate question.

MS. IVANTIC-DOUCETTE: Just a question. Can we just strike either "equal" or "appropriate" so that the sentence reads "intended with balance" between A, B and C?

DR. GREEN: I think we can.

DR. JUDSON: That's what I did. I just

left the balance.

MS. IVANTIC-DOUCETTE: Ted?

DR. GREEN: I'm okay with that.

Can I just make a comment? We're trying to decide whether we can change this 15 to 24.

DR. SWEENEY: 15 to 49.

DR. GREEN: Is this supposed to be 15 to 49? The youth indicators, though. I want to make the point that a lot of years of meetings and consultations and reports and so forth have gone into developing these impact indicators. We could change them, but after all this consensus around these indicators, part of the reason for that is so that people can have comparable data. If one project is targeting a younger group, they wouldn't have maybe comparable data with those who have agreed to these indicators.

I think changing the ages of people targeted for AIDS prevention would be such an important departure that that should be maybe a separate resolution. If we think there are reasons to do that, that should be a separate resolution. But

for purposes of this, selecting from the existing list of recommended impact indicators the ones that closely relate to A, B and C just to make sure that prevention is broad and comprehensive. So I would argue for not changing the ages for those reasons. But if we think it's important, make a separate resolution for that.

MS. IVANTIC-DOUCETTE: Just a comment. Joe is next, Lisa, David. Reverend Sanders, can you hold off on that thought?

But one question, Ted, for you. You're trying to get to the fact that there's more objective, very specific indicators there, right? Would it be possible to say in that paragraph the indicators should be specific such as those recommended by PEPFAR? So it doesn't just marry it to those particular things. But I think what I hear you saying is you're trying to capture specific and objective targets. These are not all inclusive, correct?

DR. GREEN: You mean all the things to do with prevention?

MS. IVANTIC-DOUCETTE: Right, for the outcome that you want.

DR. GREEN: This just relates to the ABC elements, and this is where we have a lot of controversy and argument and non-implementation of the policy. Other areas of prevention are not so controversial and you don't need to have a motion from PACHA to say make sure you're inclusive and you do all these things.

MS. IVANTIC-DOUCETTE: Joe?

DR. McILHANEY: I have two items to talk about. The first is exactly what Ted was saying. My understanding would be that the indicators would compare a program in Botswana to a program in Kenya so that you have some idea of the relative impact of those programs. So since these have been developed over a period of years, personally I think it would be wise to keep it. I don't think it would suggest at all to have those ages in there that we think it's fine for a 60-year-old guy to have sex with a 13-year-old. So that's the first thing.

MS. IVANTIC-DOUCETTE: Your recommendation is to keep it as is?

DR. McILHANEY: Yes, I'd recommend keeping

it as it is.

The second is coming back to a mantra I've had about the whole ABC thing in the first place, and that is that paragraph 4 I would suggest taking out. The reason I would say that is that ABC was a very defined and specific program that had a major emphasis on A and B, and for those people involved with risky sexual behavior, a C. I think almost everybody agrees that it was A and B that really caused the dramatic decline in HIV prevalence and incidence in Uganda.

Basically, all HIV programs around the world, and there are more than 100 countries now that have specific plans that they put in place, virtually none of them have done what has happened in Uganda. I think that this whole thing fits very well except that one paragraph. I personally would keep the appropriate balance in that paragraph we were talking about earlier, but I just think it's really imperative that we not somehow cloud the fact that there has been one program in the world that has had a countrywide impact such as we've not seen anywhere else, ever. So that's the only thought I have about that.

I like the resolution. I think it's good. I would suggest taking that fourth paragraph out.

MS. IVANTIC-DOUCETTE: So your recommendation is to strike the fourth paragraph? Do either of you want to comment?

DR. McILHANEY: And I would leave the "appropriate" in instead of "equal to."

PARTICIPANT: Just to clarify, which is the fourth paragraph?

DR. McILHANEY: It's the one "whereas the ABC approach is not a one size fits all population and emphasis placed on intervention components need to coordinate the target population." I don't disagree with interventions being custom fitted, but the suggestion to me is that any time you do something with A and B and C, therefore it's going to duplicate what happened in Uganda, and the fact that there hasn't been but one ABC program that's really had the dramatic impact --

DR. GREEN: Well, just to maybe get the other side of the argument, one of the PEPFAR countries is Vietnam. Vietnam is a different type of

epidemic. It's highly concentrated among IDUs, sex workers and their clients. So maybe the argument there would be that the condom intervention would be more important than A or B for sex workers and IDUs. So that's why the emphasis placed on components according to the different needs of the target population.

DR. McILHANEY: I don't disagree with that.

MS. IVANTIC-DOUCETTE: Lisa?

MS. SHOEMAKER: Pass.

MS. IVANTIC-DOUCETTE: David, you're next.

DR. REZNIK: I'll pass to the Reverend.

MS. IVANTIC-DOUCETTE: Okay. Reverend Sanders?

REVEREND SANDERS: Thank you.

One is I would strongly encourage that you keep the fourth paragraph in, and you said it, because it speaks to exactly the point you just made, that it really is the case that there are some variables in countries that mean that you don't necessarily get the same result from the exact same application. We also

know that Uganda's success has not been easily replicated in other places. I mean, it's being used, and we're getting some results.

PARTICIPANT: It hasn't been tried in too many places.

REVEREND SANDERS: But I'm just saying we do have one example.

I want to go back to something that was suggested a minute ago, and that is that I heard you saying that what we want to do is be affirming of the President's position and how he has shaped his message. I think we can do that and not have this section in here with the indicators. I think that that could easily be a separate motion, a separate resolution, because there's nothing about I think what the President was trying to achieve with the spirit of advancing ABC that requires us to include the reference to the indicators as it is presented here.

I mean, what are we trying to achieve? This is the way I heard you say it, that we're trying to achieve this council being affirmative in terms of the President's position. I think that the President

made his position without the reference to the indicators, and I'm saying we can be affirming of his position, understanding that what has clearly come to be the PEPFAR indicators that are accepted, they are what they are. They also can change according to the country and what could be some very different circumstantial realities. So I think we get our impact without getting bogged down in that argument.

DR. GREEN: Well, if I could answer that, I don't think it's getting bogged down. Programs around the world affirm the President's and PEPFAR's ABC policy, but then they go ahead and do AIDS prevention as before there was this policy. This requires programs to actually implement all of the ABC policy. This whole program is for monitoring the evaluation standard that is already out there. But if we say all prevention programs should have all these elements, then we're going beyond saying we agree with the policy or we're affirming it.

REVEREND SANDERS: That smacks in the face, though, of your example that you gave earlier about Jamaica. You see, I think that you have to have

some affirming of the integrity of the countries that we work with and support. You see what I'm saying? I appreciated the argument that you made earlier, and I don't think that we necessarily want to superimpose. There's a way in which I think that we have to believe that there will be some integrity within those countries.

Now, are you telling me that you think there's been already so much evidence of inconsistency in it that you wonder whether or not that can occur? And if we need to provide some guideline, perhaps there's a way to do it without too narrowly defining the seascape.

DR. GREEN: To make sure I understand you correctly, are you feeling that this policy or this motion is somehow pushing a model on all the countries of the world, like a cookie cutter approach, something like that? Is that what's behind your --

REVEREND SANDERS: That's at least a part of what I'm saying, yes.

DR. GREEN: Well, what I'm saying is that we're already doing that. All the countries of the

world -- is there one country in the world, any country in the world that's not doing condom promotion, condom social marketing, community-based distribution of condoms, any country that's not doing voluntary counseling and testing, any country that's not diagnosing and treating STDs? We already have a universal approach. All the countries in the world are basically doing the same thing. The ABC policy, I argue, broadens AIDS prevention beyond -- all those things I mentioned are risk reduction. This adds risk avoidance to risk reduction and broadens the approach.

REVEREND SANDERS: I don't see anything about what we've said here, though, that is not mandating exactly what you're asking, that ABC be applied in all situations where the PEPFAR dollars go and that it has to include A, B and C. That's already clearly stated here.

DR. YOGEV: But the unfortunate part is accountability. You go to a country and you find out that they say they do A, B and C, and they're really doing the A and the B. Just show me what you did in the C and why you don't want to do the C. It's quite

broad. That's not restrictive. But we thought when we did it to put some accountability and not just tell me ABC, and then tell me you did it. Show me what you did, how much, so we see. How can we know if it's working or not? Look at the controversy now about the ABC, even in Uganda itself. From a certain area in Uganda, somebody comes around and says it's only the condom which works, forget the A and B.

I don't personally believe that. I think it's important, but not the only one. So if you have in Kenya versus Uganda versus Thailand I did ABC, here's the change in the A, here's the change in B, here's the change in C, very minimum, you have accountability to the program. You see if it's working. That's the reason why it's here.

MS. IVANTIC-DOUCETTE: Joe wants to go on this subject as well, and then Hank as well, before we come back to you, Reverend Sanders.

MR. GROGAN: When we were talking about scrapping paragraph four and some of the discussion when we talked about Vietnam, to me, if we identify a discrete population like in Vietnam that primarily is

prostitutes, and your intervention is C, that's still the U.S. government's ABC approach because you've identified why you're only using C. So I don't think that's a justification for scrapping paragraph four, necessarily, or saying that that's not in keeping with ABC, because you've analyzed the situation and you've provided a justification for weighing it in a certain way. We all agree it would be absurd to go in there and lecture about abstinence.

So my only suggestion was that maybe you take out the ABC approach, whereas no approach is one size fits all, an emphasis placed on intervention components need to vary according to target populations, recognizing the fact that in some populations it may be weighted more towards A, others toward B, others AB, and others BC, or others C, or whatever combinations you want to come up with.

MS. IVANTIC-DOUCETTE: Hank, can you go ahead? I've got you on the list.

DR. McKINNELL: Well, I would keep paragraph four and I would keep the indicators, for a very practical reason. These are public dollars being

spent, and there's a lot of public support. But there are reporters in the field right now digging for horror stories, and they will come forward. Unless we have real data to counter that wave of media that's going to wash over us here, I think we could lose the whole program.

Secondly, I think we all know that some of these programs will be more effective than others, and we need to know that. We need to continue funding the ones that are successful and stop funding the ones that aren't successful. I don't know how you do that without data, so I'm in favor of both paragraph four and the indicators.

MS. IVANTIC-DOUCETTE: I have Anita next, and then Frank.

MS. SMITH: I agree with you, Hank, on all the points you just made. I had a suggestion here in the language where "appropriate" replaced "equal." We don't say anywhere in here that I see that we want the approach to be appropriate based on the country in which the program is being implemented, and we might be able to fit that in that paragraph. You could read

"appropriate" in many different ways, I agree. It's very subjective. But if we qualified it by saying appropriate to the culture or the country in which the program is being implemented, then in Uganda you would have something that would be consistent with a Uganda message, and in another country, Vietnam, you'd have something different. But at least we're acknowledging that that country's culture needs to be considered, because that's not necessarily happening right now.

We have U.S. government dollars being put into programs that may more mirror a U.S. approach than they would an approach in those countries. So it's just a suggestion.

DR. YOGEV: That's why paragraph four, Ted, in my opinion is so important, to refer to countries and populations, whatever, and we all agreed, unless I missed it, to delete the word "appropriate" and just leave "intended with balance between." So the balance will come, but that's exactly what paragraph four is, if you're in a different country, a different culture, a different population. It would address most of the examples

which we're giving here as long as you justify the balance, why you're doing it.

MS. IVANTIC-DOUCETTE: Ted, did you want to say anything on that?

DR. GREEN: Not on that, but I just want to amend what I said about Vietnam. Even though most infections in a country like Vietnam or Thailand are found in commercial sex and among IDUs, there's also the broad general population that you also want to target with an AB message.

MS. IVANTIC-DOUCETTE: Just a quick clarification before I move on, and I've got Frank, Lisa, Monica next, and then Joe. Reverend Sanders, do you want to come in here at some point? That's okay. Just raise your hand when you're ready.

Just a question, though, for Anita. Are you saying no to putting in a qualifying clause? You wanted to make a suggestion. I'm not sure I know what you said.

MS. SMITH: I understand what you're saying, and I think it could be stronger than it is. To me, when I read through it, I didn't get the sense

that we're saying we want to focus on that culture. I mean, your language is very broad, and I understand why.

MS. IVANTIC-DOUCETTE: Can you live with it the way it is?

MS. SMITH: Sure, especially knowing that that's the intent, but I don't know that it will be read that way.

MS. IVANTIC-DOUCETTE: If you do come up with something that could be specific, Anita, would you come back on board with that? That would be great.

Frank, Lisa, Monica, Joe.

DR. JUDSON: I think we continue to get tied up with the ABC. I worry about what Ed says, too, that you're taking almost a proprietary type product and experience from one country. But the core of that experience is in B, and it should be for every program that we deal with, that if a program does not somehow accomplish a very large scale, sustainable change in exposure behavior, sexual exposure behavior, it's probably not going to work very well. So call it

partner reduction, promiscuity reduction, whatever you want. It's got to result in major reductions in exposure behavior.

Uganda isn't our only experience in this area. We've got a huge one far closer to home in all developed countries where the epidemic was 75 to 85 percent starting off in white, educated gay men predominantly. There was a 95 percent reduction over three years before we had any federal program in rates of gonorrhea, syphilis, HIV, hepatitis B, and it all occurred through unmeasurable but undoubtable change reduction in numbers of partners, and that's what we're getting at. You can't just treat gonorrhea to get out of this epidemic without changing sexual behavior. You can't hand out condoms without fundamentally changing exposure behavior. You've got to get back to the sustainable, cultural, normative changes in behavior.

MS. IVANTIC-DOUCETTE: Frank, is there some specific language that you're suggesting to offer to the resolution to firm this up? Or is it acceptable to you with your comments?

DR. JUDSON: It's acceptable to me, but I think we have to keep coming back to really the core issue.

MS. IVANTIC-DOUCETTE: Okay, thank you.

DR. JUDSON: It isn't just numbers of partners. If nobody has HIV, it doesn't matter how many partners you have.

MS. IVANTIC-DOUCETTE: Right. Did you need to make any more comments before we go on? We've got quite a few people left.

DR. GREEN: Frank just said getting back to the cultural normative, and that's interesting. The implication is that in all cultures there's normatively the idea of sanctity in marriage and not having all the sex partners you want. Is that what you meant?

DR. JUDSON: Oh, no, I didn't mean that at all. I meant somehow we need to come up with programs that change what is normative behavior, like tobacco smoking in schools is no longer normative cultural behavior.

DR. GREEN: Because in the MSM subculture,

there was a normative change. There was massive behavior change.

MS. IVANTIC-DOUCETTE: This is a great conversation. Thank you. As long as it's okay, I'm going to ask Lisa to come on. Thank you.

MS. SHOEMAKER: Thank you.

I had a suggestion also for the paragraph that has "appropriate and equal." What about just slashing "equal" and "appropriate" and having in the sentence, "Be it resolved that PACHA will use its influence to ensure that the ABC model be implemented, just as the President and Congress intended, with balance between A, B and C components."

DR. YOGEV: That's exactly the change we made here.

MS. SHOEMAKER: It is? Oh, I missed it.

DR. YOGEV: Yes.

MS. SHOEMAKER: Okay. I also wanted to say remember, everybody, AIDS is ageless and it has no boundaries, period.

MS. IVANTIC-DOUCETTE: Is there a specific language change on that last one, Lisa?

MS. SHOEMAKER: We did it.

MS. IVANTIC-DOUCETTE: Okay. I'm going to just let Reverend Sanders jump in in front of you. Is that okay?

REVEREND SANDERS: I need a question answered, and that is on the indicators, this last piece that says "an additional indicator," we have indicators for A, B and C, and then there's a piece that comes in which in our copy is highlighted.

MS. IVANTIC-DOUCETTE: "And an additional indicator that provides a measure." Is that the one that you're on?

REVEREND SANDERS: Right, right. Explain that to me in terms of why we --

DR. GREEN: Okay, I think I can explain that. The indicator that's most often used and cited, at least in developing countries, and that's where PEPFAR is -- the denominators are those either involved in commercial sex or having multiple partners, and that's important. But it's also important to have an idea of what all the people are doing in that population. So it's good to have a

condom indicator where the denominator is everyone. So that indicator that is already out there, condom use, last sex with any type of partner, any category of partner, is a measure of condom use in the broad entire population rather than in a subset of those practicing risky sex.

REVEREND SANDERS: The reason I ask is because I didn't understand. I'm appreciating the need for indicators and accountability, right? But it's inconsistent even with the way in which we have framed the earlier statements. I understand why you're saying you need indicators that fall within some very exacting parameters. That's why I understand why you didn't want to change the ages and the like. Then you throw one in that seemingly is not driven by that same logic. I mean, are there some indicators -- because I wanted to go along with the argument that Monica raised a minute ago in terms of why did we limit the age, and then I understood your argument about why you have very specifically said 15 to 24, 15 to 49. But I don't see how that holds up here because then we kind of throw it back out again

and say it's everybody.

So I don't understand that statement in relationship to the indicators. I understand what you're trying to get at. If the objective is measurable indicators that will allow us to deal with accountability, that one does not fit in the same way.

MS. IVANTIC-DOUCETTE: So your recommendation, then -- and I'm just going to reply here -- might be to just scratch that, "and an additional indicator," and that would leave that clean? Would that be what you're suggesting?

REVEREND SANDERS: That's what I'm suggesting, because if what we're trying to achieve is a method by which we're able to measure --

DR. GREEN: I'm saying this is an argument to measure condom use in the entire population, not only with those engaged in high-risk sex.

DR. YOGEV: So can you add 15 to 49 to that paragraph, the one in brackets?

DR. GREEN: That comes under the 15 to 49.

DR. YOGEV: No. If you read C, number 1 would be percent of women and men age 15 to 49.

Number 2 would be percent of men 15 to 49 reporting sex with a sex worker. Number 3 would be the percent of responders 15 to 49 years who say they use a condom.

REVEREND SANDERS: That at least makes it a logical indicator in terms of the way the rest of them work.

DR. YOGEV: I would suggest to take all this black out and just put numbers in. 1, percent of women. 2, percent of men 15 to 49 years of age. 3, percent of responders 15 to 49 years of age who say they use condoms.

DR. GREEN: Yes, take out the black, take out --

REVEREND SANDERS: I'm just saying I'm buying your argument. I think you're right about the indicators and accountability. But if you're going at it that way, then that does not fit.

MS. IVANTIC-DOUCETTE: I think that's an excellent suggestion. Does that work for you?

DR. GREEN: That's fine, that's great. The reason it was this way is just for our own

thinking. This is one that's not often used but ought to be, but you shouldn't go into our language here.

MS. IVANTIC-DOUCETTE: Thank you, Reverend Sanders. So we'll strike the bolded paragraph there and leave it at percent of respondents.

DR. GREEN: Let me make sure we're doing this right.

MS. IVANTIC-DOUCETTE: We added the age.

DR. GREEN: So there are three indicators for condoms, and it's all age 15 to 49, last sex non-martial, last sex with a sex worker, and then condom use last sex with any partner.

MS. IVANTIC-DOUCETTE: Okay, I think we have it.

REVEREND SANDERS: So we're using the parenthetical part of the statement and just simply adding to it the age. That's it, that's it.

MS. IVANTIC-DOUCETTE: So it will all be consistent.

MS. IVANTIC-DOUCETTE: I have Monica and Joe left.

MR. GROGAN: Kit, did you get that?

MS. JOHNSON: Let me just read what I have. So there's C1, C2, C3, percent of respondents aged 15 to 49 who say the used a condom the last time they had sex of those who have had sex in the last 12 months. Is that right?

DR. YOGEV: Correct, and also in 2.

MS. IVANTIC-DOUCETTE: The percent of men would also include that.

MS. JOHNSON: Oh, thank you very much.

REVEREND SANDERS: Right, so it will be consistent.

DR. YOGEV: It will be all three.

MS. IVANTIC-DOUCETTE: Is that all set?

MS. JOHNSON: Thank you.

MS. IVANTIC-DOUCETTE: Monica?

DR. SWEENEY: My question -- there are two questions, and I'm sure you all discussed it, but I would like to know how you resolved it. From a lot of the reading that I've done, and some of you who have gone to Uganda a lot, Ted and Anita, can address this, one of the major components of the success in Uganda was the leadership. We don't have anything in this

about any leadership.

Secondly, I hear and read that the President Museveni always talked about a D, and if you don't do this, you're going to die. Is that right?

DR. GREEN: Yes, that's right. That highlights the fear arousal component that Frank and I were talking about yesterday and that, in fact, I was asking one of our speakers about yesterday who mentioned fear appeals in prevention messages.

MS. IVANTIC-DOUCETTE: A couple of things, Monica?

DR. SWEENEY: So my question was how you dealt with, when you were doing this resolution, to account for those very important factors that were a part of it, and if you decided not to, I need to hear what your thinking was.

MS. IVANTIC-DOUCETTE: The idea was to keep this clean and focused with one point. We've already had an ABC motion that dealt with some leadership issues.

The other issue around D, because we have had many discussions around that, and I think there

are several of us that would include D as development, the other things that contributed besides die, whether that's access to health care, nutrition, things like that. But this was intended, I believe, to be clean, focused in this particular resolution.

DR. YOGEV: And we talk of the leadership in the last paragraph. That's specifically why we say there has to be prevention. We also address issues of stigma, gender equality, sexual coercion, so forth, without basically saying to pay for you in charge of making sure the leadership will pick it up because it's not in their task. But if those will not be addressed, the A, B and C will not work, and that's where the appeal to leadership through PEPFAR is.

MS. IVANTIC-DOUCETTE: Is that okay with you, Monica?

Okay Joe, you're up next. Frank, are you going to -- anything else registering after Joe?

DR. JUDSON: Are we seriously getting into D?

MS. IVANTIC-DOUCETTE: No, no. No, we're not doing anything. I'm just looking to get this

passed. So I think Joe is the last one.

DR. McILHANEY: Because Reverend Sanders is so agreeable, he doesn't have to listen to me again.

PARTICIPANT: Call the question.

MS. IVANTIC-DOUCETTE: I'd like to call the question. Can I have a show of hands for? Do I have to have a resolution to call the question?

All right, I'm calling the question. All in favor?

(Show of hands.)

DR. YOGEV: With the changes.

MS. IVANTIC-DOUCETTE: With the changes, correct.

Against?

(No response.)

MS. IVANTIC-DOUCETTE: Abstaining?

(No response.)

MS. IVANTIC-DOUCETTE: Note that the resolution passes unanimously.

(Applause.)

MS. IVANTIC-DOUCETTE: Thank you.

Now, the final thing that I'd like to introduce, and I'm just going to introduce it really, is our concepts that the International Committee has been working on in terms of key items that we believe need to be addressed before the end of November.

MR. GROGAN: I just want to say a couple of members did get me comments late last week that I didn't incorporate into this draft. So I'll be doing that on a continuous basis as comments are received and trying to vet them, and I'm going to work with Abner to try and set up some more conference calls with International, obviously with all the subcommittees, but to try to move this process along more quickly.

MS. IVANTIC-DOUCETTE: It looks like this. It's called "Brief History of the Global Epidemic to the Unveiling of the President's Emergency Plan." It's just an outline, and why we're introducing it is so that you have an idea of the items that we're working on. If you could particularly get any comments that you have, if you could get them via Joe to the International Committee of other things that

you're thinking about, but this is a way for us to communicate to you and into the record.

MR. GROGAN: I just would like to implore the International Subcommittee. We haven't done a good job on conference calls, and we need to make sure that we have some of these so that we can move this forward.

MS. IVANTIC-DOUCETTE: And we'd like to agree with you, Joe, on that, and we'd like to grab your calendar while the International Committee is here to at least get some basis on that.

So I don't think we need any further action on that. Thank you, everyone.

(Applause.)

MS. SMITH: Thank you, Karen.

So we just have two more things to discuss here, and I wanted to try to put a time frame on this so that we can limit our discussion and focus our discussion.

The first of the issues relates to the prevention draft that you have in your notebooks. We had said we would discuss that a bit this afternoon so

people could respond, and we'll do that, if there's comment, for the next 15 minutes, and then we'll move on to a third issue, which is a letter that would be going from the Council or from the co-chairs related to a response to the new numbers out of CDC. We felt that since we didn't have our separate subcommittee meetings to be able to craft a resolution to bring before you, yet we don't want to let that go unresponded to, that we wanted to talk to you about what you would want included in a letter from the co-chairs to the Secretary of HHS and the President in terms of our concerns and issues related to the new CDC numbers. So that's how we'll finish up our afternoon.

REVEREND SANDERS: Is there a draft?

MS. SMITH: No, there's not a draft. There's a draft of the prevention, but there's not a draft because we didn't have our separate meetings today.

So I'll turn the floor over to Monica to moderate the Prevention Committee draft discussion.

DR. SWEENEY: Thank you, Anita.

There was a draft that I referred to several times yesterday and asked everybody to read it overnight if they could so that you could come prepared to make comments. In light of what we heard this morning from the wonderful lecturer, we probably have more information to work with after hearing Edward Richards this morning.

So what I'm going to do is to ask those of you who read it and who are ready to comment if you would please start raising your hands so I can get you down and get to everyone. We're starting with Jackie, Hank.

REVEREND SANDERS: Monica, could you just say one more time what we want to achieve with this?

DR. SWEENEY: What we want to do is we want to roll out here at our next meeting a comprehensive prevention plan that we can put forward coming from this committee to the Secretary, and we want everyone to comment on what we've done and to add ideas, to say whatever you have to say as long as it's brief, because Anita doesn't want us to do it long, and then we will take all the comments back, wordsmith

it and get it out to people to comment on after we wordsmith it and put all the ideas in it so that we can have it ready to be voted on in November to pass it on. Is everyone clear about what we need to do?

So we have Jackie, Hank, Karen, Sandra. We missed you this morning. David, and we're sure there will be other people as people say things who will need -- counting on the senior leader to have something to add.

Okay, Jackie.

MS. CLEMENTS: Thank you.

First I want to offer my apologies for my flippant remark about death. I've been reminded so many times I'm going to die, I know that it's true someday. But please forgive me. Dr. Sweeney, please.

I do have some comments about the prevention outline. One is in the legal changes, I wonder if we might suggest that HIV-positive individuals be required to inform about partners, sex partners or IV-drug-using partners that they've had for the past two years in order to do partner notification and case tracking and identifying people

who may have been exposed over the past two years. We do that in North Carolina.

DR. SWEENEY: Excuse me. Do you have language in North Carolina that is regulatory?

MS. CLEMENTS: Yes, we do. We have what's called control measures for people who are HIV-positive. One is that you must inform your partner or IV-drug-using partner that you have HIV, and must use a condom even though you informed them. Secondly, you must identify to the health care professionals or the disease intervention specialists that will visit you, identify your partners for the past two years so that they can be tracked and notified of their potential exposure. Thirdly, you cannot donate organs, blood, et cetera, cetera. Fourth, you must have a TB skin test, and there is a fifth one, which also relates to partner notification.

Our disease intervention specialists do, within 30 days, go out and visit the person that's been notified because we have name reporting, and they get that information and then seek their partners for the past two years in order to inform them of their

potential exposure.

MR. GROGAN: Can we get a copy of your language?

MS. CLEMENTS: I can't. I can get you a copy of the control measures.

Also, if I might suggest that you said that anonymous testing should be available but is not preferable. In North Carolina, we fought, and I did too, actually, to maintain anonymous testing for many years, at least four I know, with the belief that if we did not have anonymous testing that people would not come out and test for HIV because they would have to give their name and identifying information. Though we were able to put it off for many years, once anonymous testing was abolished, we saw no change in the numbers of folks that actually came out and tested. Our testing rates did not change in any significant manner.

So I do believe that anonymous testing, although I fought for it for many years, I do think now can be a hindrance to identifying those who are HIV-positive, because once again people may not return

for their test results and you're left with a positive test, and because at that point you no longer can provide partner notification because you don't get that information either. So I might think that you might want to consider whether you want to maintain anonymous testing.

One last thing is that your messages must be targeted to various populations, and I sort of thought all populations, be it not just for now and those who are at risk now but for those who may become at risk in the future as time moves on, that we should target messages to everybody, because HIV is also a personal responsibility to keep yourself safe. You might include "Prevention for Positives" and "HIV Stops With Me" somewhere in here to encourage those with HIV to make sure that they don't pass it to other people and somehow figure that in this outline, and also include somehow getting the bureaus of community health centers involved, because most of our folks are seen at that level and we need to get them more involved with testing, which means they need the money to do so.

DR. SWEENEY: Thank you very, very much for that, Jackie. I wanted to say this today but Carol was running short of time, when Carol Thompson was here. Just so all of you know, the National Association of Community Health Centers already has a blueprint surveyed nationally for community health centers to find out who has programs, what they have, what they need, and we're getting together a package to help people get a start-up who don't have HIV programs, and it's being done by the National Association.

And thank you very much, because after the lecture this morning I went from reluctantly saying keep anonymous testing to I was going to start fighting for no anonymous testing, and thank you for bringing it up. How long has North Carolina had it?

MS. CLEMENTS: We abolished anonymous testing I know about five to six years ago.

DR. SWEENEY: Thank you very much.

Hank?

DR. McKINNELL: I have two points. One is second page, third bullet, using fear as a behavior

change. The continuing enslavement language I personally find very offensive. But more importantly, it would be very offensive to my 12,000 colleagues who devote their life to finding new medicines to keep people alive and maybe one day cure this disease. So I would only ask that we be a little more temperate in our language, and that applies to all of us, by the way, not just whoever put that language in.

The second is under .2 on the first page. It's bullets 2 through 4, which seem to be kind of related around advertising. I'm not quite sure what we're trying to get at here. If whoever has these concerns talks a little bit, I may be able to craft some language that's more precise that gets at this, because I certainly agree that we shouldn't be using rock climbers as models for HIV drugs, that we need to communicate the benefits of medicine within the context of the horrors of HIV. I have no problem with that at all. But I'm not quite sure what your reaction would be, for example, to an ad featuring Brent Minor running a marathon, because it is true that these drugs bring enormous benefit to some but

not all people, and they're not the complete answers.

If whoever has these concerns talks a little bit about what you're trying to get at in these four bullet points, I'll try to craft some language that we can all agree to.

MR. GROGAN: I think it's easier to conceive of them as two different concepts. The first two go together, and points 3 and 4 go together. The message is targeted to various populations, and the model of tobacco is geared toward government public service announcements and philanthropic ads.

DR. McKINNELL: So 1 and 2 go together.

MR. GROGAN: Yes.

DR. McKINNELL: Okay, I understand that. And 3 and 4 go together you're saying?

MR. GROGAN: Yes, I think so. I think that there was concern, and I think some of that was alleviated yesterday based on what some members said to me. But there was some concern about the direct-to-consumer marketing images, and that's where those two points came out. But maybe some of the members can --

DR. McKINNELL: Well, I share that concern. I'd just like to get a sense of where everybody is, and then I'll try to craft some more precise language.

DR. SWEENEY: Is that to answer Hank's question directly right there?

DR. JUDSON: Pretty much.

DR. SWEENEY: Okay. Could you limit it to answering that so I can continue on the list? So please answer him. Thank you.

DR. JUDSON: What I think we all agreed on is that anything that intends to glamorize or minimize the extremely devastating consequences of a lifelong incurable, expensive, terrible infection with drugs with lots of side effects is not performing a service. The fear that we were referring to was the fear that we discussed yesterday, that we want to make sure that people know that getting HIV, however, will not get them to where they want to go in life, just like tobacco smoking and the Virginia Slims type ads.

So we are talking about eliminating promotional glamorization of HIV or its treatment. We

are also talking about going over the other side and mounting what might be known as counter-advertising where we're not really countering the pharmaceutical industry. What we're doing is countering any advertising or any impression that tends to minimize what HIV infection is and does. Being enslaved to drugs for those is a reaction to the advertising that appears to make drugs totally liberating. In fact, it isn't very liberating to have to take the number of drugs that people do and to be subject to the clock, to concerns about resistance, to side effects, to when they take their meals, everything else.

"Enslavement" -- I don't know, maybe it's not the right term, but it is being used out there. I have gay activist friends who are out doing interventions in bathhouses and so forth, and that's exactly what they're saying. They're saying "I've got HIV, and a number of my colleagues do, and this is what I'm having to do and put up with, this is how my life is."

DR. McKINNELL: Well, I agree with all that, but we have to have some balance here. There

are some benefits to these drugs, too. Brent Minor does run marathons, which he couldn't have done -- he wouldn't be here if not for these drugs.

DR. JUDSON: But this is the Prevention Subcommittee, and what information are we trying to get out to motivate people not to get HIV? Does Brent running -- this is a different issue altogether. The drugs have been an enormous success and are clearly lifesaving. But if we're trying to prevent, get somebody to change their fundamental exposure behavior so they don't get HIV, do we show them pictures of Brent running a marathon or people repelling, or do we show them what a really bad disease this is and that you need to do everything you can to avoid it?

MS. CLEMENTS: I would hope that we would show them some of the truth, too. I'm not enslaved to any medication. It's not always easy, but a lot of medications aren't easy. Cancer medications aren't easy. So we who have them available to us are very grateful, most of us, to be able to have them, though they may not be always easy.

DR. SWEENEY: I'll get your name on the

list. Oh, your name is on the list but you're not next. That's always difficult, but hold that thought.

Let's see, Karen is next.

MS. IVANTIC-DOUCETTE: Well, just on that point, I agree with Hank. I think using the term "enslavement" is not a good one. I also am concerned again about language, which is really, really important. But fear to promote positive behavior change seems bizarre to me. Maybe something more like negative messages to promote behavior change. Anyway, it's just a language thing that doesn't sit well with me. It feels very punitive, fearful, enslavement. The language isn't good. I think you're trying to say we need negative messages to get behavior change.

But anyway, my key point goes under behavior change. There's a lot of data out about behavior change, and I think the terminology again becomes important. Under behavior change you have "individual behavior must be changed by changing what is accepted as a behavioral norm through the law." I'd like to suggest that we start thinking about individual behavior change as personal behavior

change, again separate from public behavior change, which I think you're trying to get to when you're trying to change a norm as acceptance within the public spectrum.

So I think that thinking about that language differently, because I think changing personal behavior is quite complex, it's ongoing, it needs a variety of strategies, it's something different, and as I read this statement it seems to me that you're saying by changing the law. I mean, it seems too simple. I just wonder again, thinking in language, saying something in terms of personal behavior change can be impacted by public interventions such as changing what is acceptable behavioral norms through legal methods or media messages, which comes in on your second point, or changing concepts of education about what is acceptable, so kind of tying in all your bullets under a public intervention thing, but being very clear about what's personal and what's public, that the public intervention does impact on the personal but not confusing the two.

Then also looking at point number 3 under behavior change where you have individual behavioral change, but you have consistent messages tailored for various populations. That seems to me, again, public behavior change, not personal or individual. So I'm just thinking about if it would be helpful, at least it would be helpful to me to kind of think about those terms differently and the interventions associated with those.

DR. JUDSON: Let me explain that this is not a resolution. I think the problem we're having at this point -- and I'm speaking because I'm one of the ones who initiated this. We need a new approach in a number of different areas so that the newer concepts are listed here. I don't think they're expressed well in certain instances, as you pointed out. But the question is, are these new directions, new initiatives, new approaches acceptable to the group? If we get the concepts right, then the specifics and the wordsmithing I think can come out later, like advertising, as you were saying. What are we trying to communicate to change people's behavior?

When we got into the issue of laws, we were dealing with the subject of what laws do we need, public health laws to criminal laws, to support certain behavior change? One of the examples is DUI laws. DUI laws clearly restrict people's ability to go out and drink and drive, but they change a normative behavior and they result in people thinking real hard about what's to gain and what's to lose if they went off drunk.

MS. IVANTIC-DOUCETTE: I'm not disagreeing with any of your interventions as you have them, just the language and the way you conceptualized them, because I think, again, behavior change, education message and communication contributes very little actually to overall personal behavior change in this field.

DR. JUDSON: That's what we all agree on.

MS. IVANTIC-DOUCETTE: So I guess I'm just saying that in terms of your bullet points, yes, they're great, the concepts are good. But I think the way you frame it in language does become kind of important.

DR. SWEENEY: Between personal behavior and public behavior.

Thank you, and we're on to Sandra McDonald.

MS. McDONALD: Thank you very much. I, first of all, appreciate that you've taken the time to develop a strategy, but I must say that your first statement, that prevention must be the central component of any effort to combat HIV, makes me feel like there is a contest between prevention and care. I think "must be central" is not appropriate language to also include care but should be one of the many components, because again I think it's an only statement, and I think the only statements don't work.

I also am appalled and feel that under number 1 the legal changes absolutely demean people living with HIV. I think all of your words where you say "HIV-positive people should" might need to be "should be encouraged." If you're not running an agency every day and looking at people living with HIV, most of this is impossible because we're in a fire. We're not in a place where we put the fire out

and we're able to do this in-depth sort of conversation.

Sure we need contract tracing, but a lot of our folks who have been addicted for 25 years can't remember who they were with last night. So that's the reality of the lives that we live in. I'm sure your intent wasn't punitive, but this wording actually sounds like it's an attack on people with HIV, and I, for one, would not ever be able to lend my vote to that language. So I'd like to work with you and others who might be interested in drafting some language that we might be able to present that would certainly represent what you're doing. I think Jackie has already hinted at something that's already in law. Also, soften the attack on people who are positive.

MS. CLEMENTS: Can I respond to that?

DR. SWEENEY: Can you hold that thought?

MS. CLEMENTS: Yes.

DR. SWEENEY: Because we have to get to David, whom I asked to hold a thought before.

DR. REZNIK: I'm going back to the discussion between the two gentlemen on the other ends

of the table. We're talking about mainstreaming the epidemic, we're talking about eliminating anonymous testing, we're talking about a lot of changes, and I don't think while you're doing all of these changes that you can eliminate hope because we have a group of people that is dealing with this disease who are already used to stigma and discrimination, but the hope should be based in reality.

So if Brent is the reality, he should be portrayed, and our lovely southern belle over there should be portrayed, and my partner should be portrayed. I think that we have to be real there. I thought that was too much.

The other point that I wanted to make is that I know leadership is mentioned here, but we need leadership within specific affected communities to come forward, and whether that is political leadership or religious leadership or leadership in entertainment, whatever that might be, then it needs to really be a key part, because it's my understanding that that's what helped the great reduction in Uganda.

DR. SWEENEY: Thank you, David.

We have it down, a spectrum of portrayals.

Ted?

DR. GREEN: I wanted to say something about the behavior change bullets. But as far as the comment that was made about whether prevention ought to be a central component, that's a fundamental principle of public health, and I'd say especially when we're dealing with a disease where the treatment is very expensive and long term. I would be in favor of keeping this for those two reasons.

The first two bullets on behavioral change, Frank made a very important point a little while ago, and he's made it before, which is that behavior change should be aimed at reducing the number of exposures, and that is another fundamental principle of public health when we're talking about an infectious disease, whether it's measles or mumps or syphilis or HIV. When you think about it, before recent policy changes, our programs were not aimed at that, at limiting the number of exposures.

Risk reduction measures such as male and female condoms and microbicides, when they're working,

will not necessarily limit the number of exposures, whereas partner reduction, monogamy, fidelity, abstinence, delay, those things do limit the number of exposures, and I think that's such an important point that it ought to be a bulleted point, that behavior change should be aimed at limiting the number of exposures.

DR. SWEENEY: That's also important because as you increase the number of exposures, not only the absolute number of exposures but the earlier you start, which also tends to increase the number of exposures, the greater your risk. So we will definitely make sure we get it in.

Lisa?

MS. SHOEMAKER: My brain juices are flowing now. At first I thought everything was good, but now I have a few things I'd like to see happen also. One of them is I'd like to see personal responsibility built into this, because as a person living with this disease, I have become responsible for myself in many ways, to take the burden off the medical field, medical doctors because they're

overworked; number two, because I'm a very aggressive person when it comes to my own care and I know what's best for my body, and I'm not afraid to say no when I'm forced by someone else what they think is best for me when I know it's not.

That's one of the things, just for behavioral change, for a suggestion, individual behavior must become personal responsibility by changing what is accepted as behavioral norms through the law. That's just a suggestion for maybe how we can get "responsibility," that word in there somewhere.

The other one would be on page 2 under "Information Gathering and Analysis," somehow getting testing, that HIV must become a routine part of primary care in the U.S. Everyone should know their status and become responsible for themselves. That's another suggestion.

The second one was I'd like to see a change in number 2 under "Behavioral Change." The first bullet says messages must be targeted to all people, groups or populations. To me, a population or

a people group is the same thing, or an ethnic group. Is that correct, or am I mistaken? I'm not sure, because to me population means everybody.

DR. SWEENEY: Just to clarify what that meant, we were talking about the fact that there needs to be targeted messages for specific populations. So the message that you would give to a senior group, which is often not addressed at all anymore, would be different than the message you would give for a subpopulation of adolescents. So that was our thinking. I don't know how we ended up saying it, but that's what the thinking is.

MS. SHOEMAKER: Okay. That I think is fine for targeting various populations, but it needs to include everybody.

DR. SWEENEY: Yes. The message should be specifically targeted to the population it's hoping to reach and not think that one message is going to reach everybody.

MS. SHOEMAKER: Okay, right.

DR. SWEENEY: Thank you, Lisa.

Joe McIlhaney?

DR. McILHANEY: Frank said what I was going to say, and that is that we meant for this to be a concept paper, not a document to be published. Ultimately perhaps it might become that, but there are a lot of really significant issues here that I think are really important for us to deal with.

Sandra, you were talking about how you never could vote for something like this. Tell me if I'm wrong, but I would assume that if I have HIV and I offer myself to you to have sex and I don't tell you I have HIV, that you'd be highly offended at that.

MS. McDONALD: Well, I have the choice to either have sex with you or not. It also is my choice.

DR. McILHANEY: Well, if I don't tell you I have HIV --

MS. McDONALD: It's still my choice. I'm not going to take myself away from making that choice.

DR. McILHANEY: You wouldn't care whether I told you I had HIV or not?

MS. McDONALD: I always care. I understand how HIV is transmitted. With 6,000 clients

and counting, I certainly understand. But what I was saying about the language is that all of it sounds so punitive. I'm sure that wasn't the intent, but it just sounds very punitive, each one of the points.

DR. McILHANEY: That's my point. That's my point, that the language may not read right the way it is right now, but I think probably most of us would agree with most of the concepts here.

My point is, then, the goal of the committee was to get down to some of these things that have sort of been elephants in the room that we really haven't ever talked about or maybe haven't had time to work through them so that we as a group can say, look, it's time for us to start treating HIV as what it really is, and that is a disease that we need to really get serious about, to eradicating.

So I hope that helps some, and maybe what we do is -- I don't know, Monica. Maybe we work through each of these over the next meeting or two?

DR. SWEENEY: No, not the next meeting or two. We're asking that everyone -- we're putting down everything that's being said. We're going to try and

rework it.

There's something that hasn't been said that I'm going to ask everybody in a minute, but we have three more people on the list, because we need to have a little discussion about it. But what we're going to do is to incorporate what is being said, get it out to you, get some comments on it, and when we come in November we hope to have it in a form that we can have it adopted as a prevention plan from this committee. That's what we're hoping to do.

Reverend Sanders?

REVEREND SANDERS: I think your last comment, Joe, was very important, and that is the idea of a concept paper, because I think the real issue in developing this to a point that we can embrace it as a council is really going to have to do with language. If you noticed, over and over again, what Hank said, it really is a matter of language. I would remind you, though, that when you look at the issue of legal changes, even when Ed Richards was talking, one of the things he said about what might have been optimal in terms of being able to control the spread of disease,

he even framed it in terms of being at a period when Draconian powers existed, and I think that we're not talking about reintroducing such an era.

So one of the things we're going to have to do to make this work -- and it's in his notes. I went back to make sure it was in the slide the way he said it. What he's saying is that -- I often think that I might make a good benevolent dictator. But I guess what I'm saying is we want to make sure that language does not lend itself to that kind of interpretation.

Then the other thing we have to do in this -- and I will help work on the language here -- is you want to make sure that you leave nothing there that lends itself to any kind of selective enforcement. How do you enforce -- standards of culpability end up being very difficult to frame in law. So we're going to probably have to get some good legal minds to help us to make sure that in spirit we say what we're trying to say in this concept paper but in no way introduce the suggestion that we are advancing a posture that in any way compromises rights as we know

them in this country, and we have to do this all the time.

That's the great argument that's going on right now with regard to a lot of the things that were the byproduct of 9/11 and the like. So that argument is going to always be there. But I'm saying that we ought to make sure that we fine-tune in a way that gets us beyond that point.

The last thing is I would hope that in terms of process, that we could figure out how to do this, and this is strictly a process question, in a way that does not bring it back in November at a point where it really has to be a consuming process for this group. I don't know if it's going to be the conference calls or what, but I can see a lot of hard-nosed, tough conversation, as well as language and wordsmithing is going to have to occur. I just want to make sure that we set some kind of procedural process that allows that to be done in advance.

MS. SMITH: That was part of what I was referring to at the beginning of this session where I said you'd be hearing more from your committee chairs

as to the process, timelines, et cetera, so that we can all be on track for that.

DR. SWEENEY: It is important, however, mentioning timelines and process, that you do know that anyone who wants to work with us on this during this process, which is going to be difficult, know that we have a conference call the first Friday morning of every month from 9:30 to 10:30, every single month, 9:30 to 10:30 eastern time, and it's very important, eastern time, because we do have people in different time zones, and we have been doing that for a long time. We will continue to do it faithfully, and to make sure that everyone knows this, I will ask Joe to make sure that everybody in the committee has the information about calling and so forth so that you can participate.

The other thing that you said, Reverend Sanders, and I need to just say this. I was just writing this to Anita, why we're going to take another few minutes, or needed to. There was a physician working in the center where I was working taking care of patients with HIV, and there was one person who

1 came in on four or five different occasions with a new
2 sexually transmitted disease. We actually lost this
3 doctor over the fact that nothing was done. He could
4 not deal with the fact that there was no way to have a
5 person that was knowingly spreading HIV that he was
6 treating, to patch him up to go out and get another
7 sexually transmitted disease.
8 Of course, in the process of him getting a
9 sexually transmitted disease, he was probably
10 transmitting HIV to someone. So when you say we don't
11 want to re-institute Draconian laws, one of the things
12 that was talked about this morning is the public
13 health laws that are already on the records, and there
14 are times when there are people that need to be
15 subjected to some of those laws. I want us to try and
16 keep our minds open to the fact that we're not
17 criminalizing a disease state. But there are people,
18 when you use a weapon of -- there's a term for it, and
19 I will get help.
20 But there are times when your body can
21 become a weapon of destruction, and people use it that
22 way. When there are extreme cases of that, we should

have some recourse. So we are going to have to leave it on the table.

REVEREND SANDERS: Monica, I definitely understand you. If you noticed, there's one thing I said, and that is to make sure we structure what we say in a way that does not lend itself to the exploitation of selective enforcement. For instance, the same thing is true in terms of DUI, but we do know that racial profiling is real. You understand what I'm saying? So we have to make sure that in our statement, we do the best we can, not to lend it to that. But I think you're right, there has to be some accountability.

DR. SWEENEY: Thank you for your caution.

REVEREND SANDERS: To Sandra's point, let me also say we need to structure this such that we do say something about mutual responsibility, because as much time as we spend dealing with trying to get out messages of prevention, I would like to think in that scenario that you proposed, Joe, that Sandra would have also been responsible enough to say, if we're going down this road and I don't know any more than I

do about you, that I will take every step I can to guarantee limiting my vulnerability.

DR. SWEENEY: Jackie?

MS. CLEMENTS: In response to that, I do very much agree with that. I think we have to promote responsibility. However, I do know that moving to zero transmission rate for HIV is going to take some tough, tough changes, and some touch decisions. The language that we have in North Carolina related to control measures is strong. Now, how we enforce them is different because they can be difficult to enforce. But it is strong language, and I tell you, I'm tired of telling 14-year-old girls they have HIV, okay?

Now, I got it, and how I got it, that's my business, but today is a different day. We've got to take some strong action. So I think that we should have some responsibility. People who have HIV must take some responsibility. Grown folk with HIV must take responsibility not to pass this to anybody else, and that may not be a good, popular notion.

But another thing, one other thing is where you have fear to promote positive behavior

change, fear not of HIV-positive individuals. I don't know how you're going to use fear to promote behavior change and not let that overflow into fear of people with HIV, and I think you really need to think about that.

DR. SWEENEY: I have been given my marching orders. Here's the story. Committee members on Prevention can't talk. We can't talk anymore. I can only talk to calling people. That's what I've just been told.

So Cheryl Hall, then Hank, Karen and Ted.

MS. HALL: I recognize that we have lots of work to do on this document. However, I do believe that the language in information gathering and analysis is pretty decent, and I'd like to make sure that we get that, just this piece over to Carol Thompson as she prepares the final document for Ryan White, because there's some stuff here that she really needs to pay attention to.

DR. SWEENEY: Thank you.

Hank?

DR. McKINNELL: Well, as evidence of what

many of you said, I guess Karen started, what's important here is language that unites us rather than divides us. Frank and I, who usually are on different ends of issues, have now agreed to some language, which I think we would both accept, and it's around this image of pharmaceuticals.

"In the marketing and advertising of life-saving medications that benefit HIV-positive individuals everywhere, pharmaceutical companies should take great care not to detract from important messages of the devastation resulting from HIV infection, a lifelong, incurable illness." That's something I can support. I agree with that, but it's said in a way that doesn't -- it's got fair balance I guess would be a good way to put it. There's great benefit, and we can't detract from other important messages.

MR. GROGAN: Hank, if you could give me 100 more pages of that, I could take the summer off.

DR. SWEENEY: Karen?

MS. IVANTIC-DOUCETTE: Thank you, Monica.

Mine is on the information gathering and

analysis, as well. In bullet number 7, where you have "data must be shared," prisons, the military, blood banks, I was confused what "all colleges, not just HBCUs" meant.

DR. SWEENEY: Historically black colleges and universities, where there's been a lot of media attention about the outbreak of HIV on historically black colleges. So what that meant was that information from all colleges about outbreaks of HIV and STDs should be shared, not just HBCUs.

MS. IVANTIC-DOUCETTE: Okay. I interpreted that differently, like you wanted the colleges to receive information about the people that were HIV infected. So again, it goes to language in conveying your thoughts. So if you could kind of clean that up a little.

DR. SWEENEY: Ted?

DR. GREEN: This is another example of where I had my hand up because of an earlier comment. This is about accountability and responsibility.

I like what Jackie said, that if we're going to bring down infection rates to zero, we have

to make some tough choices and do some things that we haven't been doing in the past. Amen to that.

There was an AIDS summit at Harvard a couple of months ago, and a young man told a story, which is after he found out he's HIV-positive, he's ever since been on sort of a spree, picking up sex partners through the Internet, having lots of sex partners, not revealing his HIV status, presumably infecting lots of people, and not one person in that auditorium of hundreds of people said anything. We gave him a humanitarian award.

I think we've gone a little bit too far in only considering individual rights, if you can even construe that as a right to live the lifestyle you want to live, without balancing it with public health and social responsibilities. But not one person said anything like maybe that's not such a good idea.

DR. REZNIK: He was given an award for infecting 1,000 people?

DR. GREEN: Yes. I mean, he wasn't being given an award for that, but it had already been planned to give him an award. I don't think the

organizers knew what he was going to say. So he said what he said, which is that he's going around infecting people, and the award was still in the works, so they gave him the award. Everybody clapped. Nobody said, gee, you're killing people.

DR. SWEENEY: We have one more person before you.

David?

DR. REZNIK: Well, I guess I already started my response. That's not the norm. I actually saw a copy of this and think that we need to concentrate on the norm.

My question is a process question, because Treatment and Care will be coming up with a similar document, and Prevention is going to have one, and I assume International is going to have one. I don't want to come to the next full meeting to see a draft. So make sure that we see this as it goes --

MS. SMITH: We talked about this. You may have been out of the room. We will be talking with all committee chairs in the next couple of weeks to get a timeline and a process in place so that when we

come back together, we will have all had chances to see hopefully multiple drafts and have many opportunities for input on the language, et cetera.

DR. REZNIK: Can you imagine all the wordsmithing on two pages, and if we have 100 pages?

MS. SMITH: Oh, I know. That's why we started this session with little discussion about what's coming up in terms of the work in the next few months, between now and our next meeting.

MS. HALL: Could I just recommend that you put, like, Draft 1, 2, 3, as we keep changing them, so we'll know which one is the last one?

DR. SWEENEY: Sandra?

MS. McDONALD: My final comment is I offered at the end of my comments that I'd be interested in working with this committee in doing some language changing. I certainly understand the concept and would be interested in the changes. Anyone who is insane needs to be known as insane. Anyone who knowingly goes around and infects anybody is crazy and insane. My comments weren't at all trying to protect people from disclosing their status

to others. We face that every day in one way or another. But I do want to be a part of working with whoever is on the committee as we do this language, and I'd be interested in maybe Jackie and I working together, seeing what North Carolina uses. Georgia has similar laws, and we've enforced it as an agency. We've absolutely had several people locked up, just locked them up if they weren't doing the right thing.

So there are two parts of this equation. I just thought the language was a little strong and punitive, and I'd love to work with the committee on that section.

DR. SWEENEY: We appreciate your joining us, and this is where we will get it done, with all this input from so many experienced people.

I just wanted to say to what Ted said, I went to a PUSH meeting, Reverend Jesse Jackson and that group. There was a man who had been in prison, and he gave the same story, all the people he had been with in prison. When he was asked whether he used any barriers or anything, he said of course I didn't tell anybody or do anything because I didn't want to be

ostracized, didn't want to not have fun.

So I do think we have a lot to do. What we've been doing has not worked. The epidemic is still around and getting worse. So we do know we need to try some new things, and we're looking forward to working with all of you, and thank you for your input so far.

Back to you, Anita.

MS. SMITH: Hank, you had a comment?

DR. McKINNELL: Like David, I had a process question. It struck me for some time now that the strength of this group is twofold. One is our diversity. Second is the trust that we've built up over many meetings here. It's true that a number of us, at least the more active members. are rotating off of this council at the next meeting. So to David's point, I think we've got a window in time here to actually get something done, and we've got to make sure our scheduling and meeting schedule doesn't interfere. We need to produce a result by the next meeting or a number of us won't be here.

MS. SMITH: That's right, and thank you.

That's why the timeline. I know it will be a challenge in many respects, but I think that it's important for us to do it, and I think we can all be pleased with the result.

One last thing, and I don't want to keep you much longer. We went about an hour over the 15 minutes we were going to spend, but again, because our concern is that we don't want to not respond to the new CDC numbers, I think it would be a mistake for us to stay silent about that as a body, yet we don't have a resolution crafted to adopt. I wanted to, first of all, find out if you would be open to a letter going from the co-chairs to Secretary Leavitt and the President expressing concern about that, that would touch on some of the issues that we have discussed here in the last couple of days: routine diagnosis, partner notification, rapid testing deployment, and grave concern over the disproportionate numbers in terms of these new numbers of cases.

If you're open to us doing that, we'd like to open the conversation to other things you would want to have included in that letter.

So I guess the first question is, show of hands, who would be open to having a letter like that go from the co-chairs?

(Show of hands.)

MS. SMITH: Okay, thank you.

So the second question is, beyond those few things I mentioned that we know we've discussed, are there other things that you'd want to be included in that letter?

Hank?

DR. McKINNELL: Well, I would make two points. I would make a very strong statement that we are at war with a virus, and we're losing. I don't think many people understand that, actually, and the CDC data is troubling in a number of respects. But the most troubling is if you're a minority woman in the south, you've got a big problem, and I don't think that's well recognized either. So to me, those two messages, as strongly as we can craft them, ought to lead in the letter.

MS. SMITH: Karen? Maybe we can just go around, and whatever someone has, then it's easier,

and there's not that many of us.

MS. IVANTIC-DOUCETTE: My comment was, just again, on leadership, not only thinking for the current leadership but suggesting that there now at this moment in time needs to be a very clear vocal leadership announcement and that this is unacceptable, and that we are going to be having to do some changes. And that will also at the stage, I think, for the paradigm shift that we're going to be trying to promote. So again, encouraging a point in time of vocal leadership that these are just unacceptable and direction to change the paradigm. Thank you.

MS. SMITH: Cheryl, anything?

MS. HALL: I'm not sure that we can put too many things in one letter. So I'd just have you be mindful of that as we figure out what are the most important points we want to get across and send a short letter. I think if we try to get too many points in one letter, we'll lose it.

MS. SMITH: Ted?

DR. GREEN: I agree with everything so far. I would say that after making the point that we

recognize that we're basically losing the war against HIV/AIDS, that therefore we understand that we're going to have to do some things differently. So PACHA is engaged in an exercise of what will we need to do to reduce new infections to zero, and that we hope to have a document by November to share with the Secretary and the nation.

MS. SMITH: Jackie?

MS. CLEMENTS: As we prepare our document to get infections to zero, I think we need to make clear that as we're making changes and making those new hard decisions, we're not attacking people with HIV but that we're asking for their help in getting this disease under control.

MS. SMITH: Reverend Sanders?

REVEREND SANDERS: I think that it is a matter of saying that we recognize we have to do some things differently, but I would encourage you to use much of what we have already developed in this committee to address the fact that we've made some suggestions, especially as it relates to the kind of question that Hank was raising a minute ago, and I

think that it just needs to be reiterated and we need to make sure that that message comes across in very, very effectively.

The other thing in the letter that I think would be very important is to do exactly as Cheryl was saying, and that is we ought to decide right now, maybe if we can, and I think you're asking us for that, maybe what the four or five basic points need to be, and I think we might have just hit them.

I think that we do want to talk about spreading the net for screening as broadly as we can, and we want to make sure that it's effectively done. I think we want to talk about name-based reporting and frame it in a way that does not compromise any of the things that we've suggested as being potentially problematic in it. I think we definitely want to talk about the issue of racial disparity and the way in which our strategies have to reflect some new thinking in terms of how we do this, and again I'd point you back to that very important resolution that we've already passed here. I might even make it an addendum to the letter so it's something people could have.

Thank you.

MS. SMITH: Thank you.

Sandra?

MS. McDONALD: When appropriate, increased funding for prevention, care and treatment when and where appropriate.

MS. SMITH: Mildred?

MS. FREEMAN: It has to be short and precise, but I'd like to add to the letter that we are losing the war, but this committee is working on a new strategy.

MS. SMITH: Joe?

DR. McILHANEY: I have about five points here, real quickly. I think that with that announcement that there's more HIV than we all thought in the country, I think CDC has been saying it's an absolutely perfect time for a letter.

One thing I would say is that the administration is very sensitive to criticism, and I think we just have to keep that in mind. I know specifically, for example, in working with Dr. Gerberding, that there's some changes that she would

have liked to have made that she literally could not do because she knew that she'd be criticized publicly, and she just couldn't do it.

So I think a very reasoned letter saying that because of this new information and because we are losing, and I would include some of what Hank said in his wonderful talk at our last meeting about medication is not going to solve the problem, maybe what he said today, that in five years 50 percent of the people are not going to be responding to drugs that are available today, and therefore change is necessary, and that we are going to be producing some recommendations for some significant change in the way this is done.

I think what that can do is, first, it can announce that we're going to be doing what we're supposed to be doing as PACHA. It can say why we're doing it, and in doing that, then we protect the administration from criticism that they will get when they change policy, which we all, I think, know is necessary.

MS. SMITH: Monica?

DR. SWEENEY: With all of the good ideas that have come up, I just want to reiterate, and someone else has already done it, that we keep the letter fairly short, that we recognize the work that people working with us have already done. I don't know if we should call anyone's name specifically, like Carol or Joe O'Neill or somebody, but we should thank people for the support that they've shown PACHA, and keep it brief.

MS. SMITH: David?

DR. REZNIK: I think you mentioned rapid testing, anything to overcome the barriers that states have put in place, that institutions have put in place, and to think outside the box and have all providers, whether they're Sandra McDonald and her team that already does outreach, or health professionals or whatever, be involved in testing. We need to test. As Dr. McKinnell was saying, you need to know your numbers.

MS. SMITH: Thank you.

Rosa, we were just going around talking about a letter, what should be included in a letter.

Did you have anything to add? No? Okay, thank you.

Cheryl?

MS. HALL: Can I just make a comment? I think someone made it either yesterday or today, which was a conference, a White House conference on AIDS. It just seems, with the new numbers and all the changes we're planning, it probably would be good timing. Just a suggestion.

MS. SMITH: Thank you.

DR. McKINNELL: You know, some other language that really resonates with me that may surprise you is I have a feeling we're all AIDS activists now. That may be an interesting way to put it. I never thought I'd say that.

REVEREND SANDERS: I'll say amen to that. Mission accomplished. Say mission accomplished.

MS. SMITH: Thank you all so much. I think that brings us to the end of our time. We're early, which is great. It buys us a little extra travel time, relaxation time.

Joe, were there any announcements for us?

MR. GROGAN: Just two announcements real

quickly. I was informed about an hour ago that our new website is actually live and up and running, if you want to check it out and give me comments about how to improve it.

Then the fall meeting dates. I may be in touch in the next week or two. They may be shifting, unfortunately, but I'll ask you to give me some feedback about new dates. They may still hold, but there is some movement on the part of the Department and maybe the White House to be more involved in our scheduling and have some more activity around that fall meeting. So when I ask for new dates or feedback, would you please let me know as soon as possible so I don't schedule something that provides a conflict for too many members? Thanks.

(Whereupon, at 2:57 p.m., the meeting was adjourned.)