Presidential Advisory Council on HIV/AIDS
Full Council Meeting

March 15–16, 1999

Embassy Suites Hotel
Washington, DC

MINUTES

Present: R. Scott Hitt, M.D., Chair; Stephen N. Abel, D.D.S.; Terje Anderson; Regina Aragon; Barbara Aranda-Naranjo, Ph.D., R.N.; Judith Billings, J.D.; Charles Blackwell, J.D.; Jerry Cade, M.D.; Lynne M. Cooper; Rabbi Joseph A. Edelheit; Robert Fogel; Debra Fraser-Howze; Kathleen Gerus; Nilsa Gutierrez, M.D., M.P.H.; Robert Hattoy; B. Thomas Henderson; Michael T. Isbell, J.D.; Ronald Johnson; Jeremy Landau; Alexandra Mary Levine, M.D.; Steve Lew; Miguel Milanes, M.P.A.; Helen H. Miramontes, R.N.; Rev. Altagracia Perez; Michael Rankin, M.D.; H. Alexander Robinson, M.B.A.; Debbie Runions; Richard W. Stafford; Denise Stokes; Bruce Weniger, M.D.; and Daniel Montoya, Executive Director for PACHA within the Office of National AIDS Policy (ONAP). **Present from ONAP:** Sandra Thurman, Director, and Todd Summers, Deputy Director.

Absent: Nicholas Bollman, Phyllis Greenberger, Sean Sasser, Benjamin Schatz, J.D., and Charles Quincy Troupe.

Monday, March 15, 1999

Opening and General Council Business

Dr. R. Scott Hitt, Chair, opened the Twelfth Meeting of the Presidential Advisory Council on HIV/AIDS (PACHA). Dr. Hitt announced that Reggie Williams, a national leader in HIV prevention for more than 10 years—especially for minority communities and gay men of color—died in February in Amsterdam. Dr. Hitt dedicated the meeting to him and to all the others who have died of AIDS. Noting that much has happened since the last Council meeting in October, he discussed the World AIDS Day meeting Council members had with President Clinton last December. They brought up four issues with the President:

1. Expanded access to care for people living with HIV/AIDS;
2. Development of a national HIV counseling and testing awareness campaign to be directed out of the White House ONAP office;
3. Progress in implementing the stated goal of a vaccine within 10 years; and
4. Expanded investment in HIV programs for fiscal year (FY) 2000, including international concerns.

Issues Concerning HHS: Dr. Hitt asked how the Council can effect movement toward these goals. He noted that several Council members had met with Mr. Kevin Thurm, Deputy Secretary of the U.S. Department of Health and Human Services (HHS), on February 22. In agreeing to have his "feet held to the fire," Mr. Thurm has already scheduled a meeting with Council people every month for the next several months.

HHS is trying to reorganize its approach to AIDS. Dr. Hitt has asked HHS Secretary Donna Shalala to come to the next Council meeting for a significant amount of time. After the Council's meeting with Mr. Thurm, Secretary Shalala responded to its earlier letter with a letter of her own, which the Council should review with Mr. Thurm. HHS has a longer timeline than the Council's on some issues, and Council subcommittees may want to meet with people here in Washington to discuss this difference. The Council's intention is to have the Research Subcommittee meet with Dr. Neal Nathanson, Director of the Office of AIDS Research (OAR), National Institutes of Health (NIH), in the next few weeks.

Funding of $8 million for the Office of Minority Health (OMH) in HHS has been left out of the budget. The Secretary had said she would try to restore this allotment but did not say when or how she would do so. The Council could bring that up with Dr. Goosby of HHS. Funding of $15 million for the Congressional Black Caucus (CBC) remains in the emergency category. The Council would like to see this become part of the permanent base. Also, there is a list of possible further funding HHS wants. What is the status of these funding proposals?

Ms. Thurman stated that she wanted people to realize that money *is* being spent, e.g., $50 million in discretionary funds for HHS. A large part of that funding went to the Centers for Disease Control and Prevention (CDC) and the Substance Abuse and Mental Health Services Administration (SAMHSA).

Dr. Hitt said that parts of Secretary Shalala's reply to the Council's letter were unsatisfactory. Council members should let Dr. Goosby know this when he addresses the group.

***Esquire* and *An Everyday Eulogy*:** Dr. Hitt noted that *Esquire* recently ran two articles and an excellent editorial taking the standpoint that "AIDS is not over." There was a degree of hype, the opposite of the widespread current view that "everything is better." Currently one-third of HIV-positive people do not even know they have the disease, one-third are getting poor treatment, and one-third are getting the correct treatment but many are worse off from having gone through sequential therapy.

Ms. Gerus said a few words about a full-length film that was to be shown that evening, *An Everyday Eulogy*, about two women, one of them herself.

Council Member Terms: Dr. Hitt brought up the fact that the Council might expect a great deal of turnover in the near future. For advisory councils like this one, the ordinary term is not more than 4 years, and 27 members of the Council will have reached that point by the end of 1999. The actual rule seems to be that old Council appointees can stay until replacements have been announced. Dr. Hitt asked the Council members to let him know whether they wished either to

leave immediately or to stay until they are replaced. It is not certain what the Administration wants to do with the Council.

Sandra Thurman, Director, Office of National AIDS Policy, and Todd Summers, Deputy Director: Update on Activities of ONAP

Ms. Thurman first discussed international issues, which ONAP has been spending a lot of time on recently. About 5 weeks ago she was in Zambia, Zimbabwe, Uganda, and South Africa. The trip was meant as a way of raising people's consciousness about how difficult the situation is regarding AIDS orphans. Uganda is the model for preventing the spread of the disease; South Africa is very shaky regarding its response. Orphan experts from the U.S. Agency for International Development (USAID) worked with Ms. Thurman, for instance, in Rwanda. Two weeks after this Council meeting, four Members of Congress and three senior congressional staff members are going to Africa with Ms. Thurman, specifically to Zambia, Uganda, and South Africa. The four African American Congresswomen traveling with Ms. Thurman are Barbara Lee (Ron Dellums' replacement), Sheila Jackson-Lee, Juanita McDonald, and Carolyn Kirkpatrick; two of the staffers work for Senators Helms and Hatch.

Ms. Thurman noted two really telling things she saw in Africa: grandmothers caring for as many as 35 grandchildren (when all the parents, the in-between generation, had died), and many families in which a child 14 or 15 years of age was head of household. She was struck by the importance of microenterprises for women in this context, a useful connection that she wanted to emphasize to USAID. AIDS is not just a health issue—44 ministers of finance and trade from Africa were to meet in Washington on March 16, and Ms. Thurman planned to explain to them that, beyond the health aspect, the AIDS epidemic also has a huge economic impact.

Ms. Thurman will be visiting the Southern African Development Corporation in April in Botswana—ministers in attendance will be from other than health ministries. Vice President Al Gore met with South African Deputy President Mbeki in February. Vice Presidential staff members said that the Vice President was more passionate about AIDS than they had ever seen. He asked Secretary of Defense Cohen to talk with South Africans about HIV in the military.

A dramatic shift has occurred in how people in the State Department, USAID, and other agencies look at AIDS. They have gone from a catalog of current programs to developing a real strategic plan on this issue. Emergency funds for the orphan program were not carried over into the USAID budget, so funds are either $3 million up or $7 million down. But people look differently on this epidemic than they did.

Some progress has also been made regarding access to care and waiver requests. The Health Care Financing Administration (HCFA) is working very hard on waiver requests, and Jeffords-Kennedy demonstration projects have $300 million. ONAP wants to make sure the initiatives are all working together.

Mr. Summers, Deputy Director of ONAP, stated that his Office has an outstanding relationship with the Office of Management and Budget (OMB), e.g., regarding the race and minority initiative announced on October 28, and Ryan White reauthorization and quality of care. FY 1999 was a banner year in terms of money available. ONAP has important allies in OMB and in other parts of the Administration in connection with needle exchange, which will raise its head during the FY 2000 negotiations. People like Elena Kagan of the Domestic Policy Council were real stalwarts, but they could not prevail against the Republicans.

Ms. Thurman stated that Dr. Gary Nabel has been selected as Director for the new Vaccine Center at NIH named after ex-Senator Dale Bumpers and his wife. A budget problem at the Department of Defense (DoD) has led to a decrease in vaccine research money there. Some people are asking why AIDS vaccine research should be done there when it is being done elsewhere as well. Work is continuing regarding microbicides.

Mr. Summers stated that the Federal Bureau of Prisons has a new medical director, Dr. Newton Kendig. Mr. Summers also mentioned the Correctional Officers Health and Safety Act, which requires testing and counseling of prisoners coming in for more than 6 months who meet certain objective criteria. He said his Office was hoping for entree to State and local prisons for the Federal Government.

Ms. Thurman described a productive meeting with Drs. Helene Gayle and Jeffrey Koplan of CDC. She said various issues get hung up at CDC. Where are the log jams? What can be done by 2000 to achieve greater accountability? Should some money be moved around? On the other hand, CDC *is* doing some great work. CDC has 1,050 FTEs (full-time equivalent employee positions) paid by HIV funds, but only 550 staffers. Where are the other 500? ONAP helped facilitate a meeting with Asia-Pacific Islanders and Native Americans to discuss issues. ONAP is working with OMB to make sure about accountability for CDC. Uganda has gone from 18 percent HIV-infected new recruits into the army in 1986 to 8 percent today. Mr. Summers said Dr. Koplan was friendly and appeared to be a real ally. He added that ONAP itself is getting a couple of new positions, plus agency representatives from DoD, NIH, USAID, and the Department of Housing and Urban Development (HUD). ONAP is also establishing a Web site.

Daniel Mendelson, Health Budgets,
Office of Management and Budget

Mr. Summers introduced Daniel Mendelson of OMB. Mr. Mendelson is in charge of health budget matters (e.g., for Medicare, Medicaid, and all of HHS) and has been supportive regarding HIV/AIDS funding.

Mr. Mendelson stated that this is a very difficult budget year. Every dollar spent has to be offset somewhere else, and funds often disappear all together. Things are very contentious. The CBC got $50 million extra for HIV/AIDS in an omnibus bill last year; OMB helped, but is not sure about this year. The appropriators do not want an omnibus bill, and there are tight overall caps. A $100 million increase is included in Ryan White, more in Titles II and III, and $50 million for minorities in the Office of the Secretary of HHS. This was formerly emergency funding.

CDC has $10 million for a "Get Tested" program. The focus this spring is on prevention. Everyone has questions as to where the money is being spent at CDC. Dr. Jeff Koplan will be an ally in CDC. Funding for NIH is a disappointment, and not just for HIV. OMB will try to work on the mandatory spending side if there are few or no discretionary funds, for instance, regarding Jeffords-Kennedy. There is a $1 billion initiative for 5 years primarily, but not only, for people without insurance, and emphasis on increased integration of local health delivery systems and funding local service delivery networks. Extreme fragmentation and little coordination are currently seen on the local level.

Comments and Questions: Council member Robert Fogel told of being at a World AIDS Day meeting with the President last December, where the President bit his lip during a story about a woman dying of AIDS who asked her friend to adopt her child. The President then said that $10 million is being set aside for special funding for orphans. But now that money has not been renewed. Ms. Thurman replied that there is still a chance that the $10 million will be renewed. She felt ONAP had created fertile ground for more funding from Congress. Both the State Department and USAID are more interested than ever in this issue of children with AIDS. Even with congressional support for foreign aid flagging, ONAP has received a lot of attention, leading to increased financial support.

Ms. Regina Aragon pointed out the relationship between housing and health care. Stable housing helps people remain stable with their health care. About the $50 million for emergency funding: the Council's understanding is that it was renewed but not as a part of the HHS base. She questioned needle exchange and the battle in Congress, as well as budget neutrality.

Mr. Mendelson said that his office would propose on needle exchanges what they had proposed last year. The congressional majority beat OMB last year. He noted that more data will probably soon be available, and the focus will be put on this point. The Secretary of HHS has made the determination that needle exchange programs do contribute to fewer AIDS cases, with no negative side effects. OMB will push the issue, but, he added, his agency's record in this area is bad. Regarding Maine's request for a waiver, he said often one doesn't change policy but reinterprets it, in this case regarding budget neutrality.

Mr. Summers asked how Medicaid looks at waivers. How are the savings calculated? For instance, what base time period is used? Different parameters yield different results, but the Administration does not have the ability to arbitrarily change formulas. Mr. Thomas Henderson said he understood that the formula is set by policy and not by statute. Mr. Mendelson replied that, in terms of appearances, Mr. Henderson was correct. But Congress trusts OMB to do things a certain way. There is a delicate balance as to how far OMB could go in changing the formula, for instance. OMB would hear from Congress if it changed the formula. Mr. Summers said there is not much support on the Hill to use Jeffords-Kennedy to address HIV in a macro sense. The political climate is not good.

Rabbi Joseph Edelheit asked how much Clinton AIDS money is really permanently there. Mr. Mendelson said one had to think of funds as short-term and long-term. OMB has regularly tried to institutionalize spending. For instance, it took minority funding out of situations where the President would have to declare an emergency to spend it. It left some money in the Public Health

Safety Emergency Fund, but paid for it. For the future, the issue of reauthorizing the Ryan White Act will be a bellwether regarding long-term institutionalization of funding. Conservative Members of Congress are raising the issue of cost-effectiveness: "What are we getting for all these dollars?"

Mr. Summers said one angle is to make "horizontal investments," to put funding into non-AIDS-specific programs. This helps preserve the funds, because they are not limited only to AIDS, while cutting Balkanization of programs. The $10 million "Get Tested" or "Know Your Status" campaigns should be used for specific target groups and new programs, using them as tests to pull in a more effective direction the other $90 million already being spent to encourage testing.

Mr. Mendelson added that it is easy to advocate Ryan White funding. People know what it is; it has a constituency. But the prevention side does not have a Ryan White type of program: "Everybody knows what it [Ryan White] is and that it works." That kind of "political traction" does not exist for prevention. Congress and others have a lack of faith in Government's *ability* to prevent. Sandy Thurman said the Council brought this up in the first place, and ONAP had to work closely with the Council to get its ideas. Mr. Summers said that the Council is trying to make its investment count for something.

Dr. Bruce Weniger pointed out that up to now Congress has put more dollars into the military AIDS vaccine program than the President had asked for, and asked why this had changed this year (i.e., no additional money). Mr. Mendelson said he did not know and would find out. Ms. Thurman said that the money was removed in Congress. There is a lot of confusion as to why both DoD and NIH are doing research regarding a vaccine.

Dr. Levine said that she is not sure anything regarding needle exchange programs could move Congress, but it appears that needle exchange has actually decreased drug use, contrary to what some had expected. This is because the exchange programs were carried out in the same locations as, for instance, methadone programs. People came in for a needle exchange and found out about methadone treatment. Regarding DoD and NIH both working on vaccine development, there is no reason why anyone should not be doing such research, as long as it is properly coordinated.

Dr. Eric Goosby, Director, Office of HIV/AIDS Policy,
U.S. Department of Health and Human Services

Dr. Hitt introduced Dr. Eric Goosby, Director of the Office of HIV/AIDS Policy at HHS, to speak on an update of the CBC's "Severe and Ongoing Health Care Crisis."

Dr. Goosby said his Office is trying to address the disparity of infection rates for African Americans, Hispanics, and other minorities as compared to the rest of the population. The CBC has helped make available around $157 million. Of that, $50 million went into the HHS Secretary's emergency fund. This money was really unattached. The rest was the result of moving funds from FY 1998 to FY 1999, expanding programs based on the '98 budget into the '99 budget, and some additional programs.

Admittedly, $157 million will hardly address the disparities about which the Office is concerned. Such disparities include longevity, development of opportunistic infection, severity of infection, point of entry into care in terms of stage of disease, and the use or nonuse of protease inhibitors and other therapies. Women are also affected by these disparities, receiving less than optimal care, for instance.

In discussions with Council members and with the CBC, Dr. Goosby's staff came up with areas where a positive outcome was more likely in the long haul. It is still an unequal playing field, however. Another issue concerns societal or cultural differences in various minority populations. Some of these populations do not have the proper infrastructures to handle the funds and programs that are available. Why do some sick individuals not enter care and stay there? The cultural context in which individuals can safely reveal themselves to these communities seems to be a very large factor. An inability to be accepted is seen in all of these ethnic and minority groups.

Dr. Goosby said his Office has tried to use already existing programs, but also to expand them and then use them to persuade OMB to give more money in the next budget. The Office wants to go after groups involved in high-risk activities, focusing on quality of care and making sure the people know about protease inhibitors and other treatments. It also deals with the problem of securing compliance and with trying to prevent or treat opportunistic infections.

A huge need exists to bring Federal funding and technical assistance (TA) to private community-based groups. HHS has tried to create the basis for providing for a more sustained Federal TA presence, and to build up TA transfer to community-based organizations. This is a crucial emphasis in the way the agency approaches minority organizations, and in how it achieves a response in these communities that can be durable. What is now just a beginning could evolve into an important resource for minority organizations and communities.

Extraordinary confusion also exists about who receives funding. Congressional language that came with the legislation did earmark some dollars for the African American population and created a chaotic dialogue about who would be the recipients of these Requests for Proposals (RFPs) as they developed. Where it says "African American," HHS follows that. But there are other instances where several minority groups are not necessarily designated as such.

Questions: In response to a question, Dr. Goosby said that CDC puts Alaska natives, Pacific Islanders, etc., into one category, "other." It is hard to identify high-risk groups among these groups when it is not known where the latter themselves fall in the overall risk spectrum.

Mr. Anderson asked how the new theory of TA can be applied when the current national system involves conferences and "fly-in, fly-out" TA. Are the funds that would be involved new or only reshaped current funds? Dr. Goosby said it is difficult to get this concept accepted on an agency level, though there is no problem on the individual level. It has been difficult to get an agency's head out of TA conduits the agency has already created. He said there are some community-based organizations, fledgling organizations best positioned with high-risk populations, for which new strategies are needed. They should be helped to become more effective.

The dollars already in the TA conduits will continue. But the new CDC funding and the $50 million emergency funds under the Secretary, which are unencumbered funds—that is, not connected with programs—are all focused on creating a new entity. The RFP would come out in early summer from the Health Resources and Services Administration (HRSA) or CDC for a community-based organization, a national organization, or even a State or municipal health department. Subcontracting to national entities could occur under this new entity. They would have a regional focus, and would have to know their way around community-based organizations and help those they know are most capable of doing a good job. This idea is new, and difficult for the Federal Government to embrace, but it is what should be done.

In response to a question, Dr. Goosby stated that a strong need exists to develop individuals among minorities and women who can become leaders—*and stay.* Those in power have to nurture leadership and work with existing organizations. They have to understand how to ensure that an HIV-infected person can feel safe in his or her community. The Secretary and the Surgeon General have been concerned about how to help make it easier to admit that one has AIDS. HHS staff have talked with the Urban League, the National Association for the Advancement of Colored People (NAACP), police forces, and others regarding this problem.

Ms. Stokes asked if there are any sanctions for doctors, hospitals, and others that receive money for minority group HIV/AIDS health care but do not do the job right. Dr. Goosby said HHS is trying to reach nurses, doctors, and others who do not specialize in AIDS but who have direct care for AIDS patients (fewer than 50 in each case). They are not dedicated HIV health providers. A lot of patients have probably not received proper medications, for instance. HHS is trying to teach their health care providers, and to make treatment more individualistic. The agency hopes to build up a cadre of treatment and prevention intervention specialists who could also help patients regarding housing and food.

Dr. Hitt said that a good understanding is just beginning of what medicines and treatments are helpful. Dr. Goosby said the Office of the Surgeon General and his own Office are implementing what the CBC has asked for. They are looking at the original documents, and are speaking with the CBC, more than is usually the case with HHS programs. They feel they have stuck by the letter of the legislation and are committed to seeing how funding pays off for minority communities.

Ms. Frazer-Howze said that CDC argued that programs should be sustained, not “fly-in, fly-out,” and that assessment should be included. Also, black ministers should be trained. But it seemed that the emphasis on sustained or permanent changes was being lost. Dr. Goosby said that it is difficult to sustain the dialogue: people say everything is fine and then go down a familiar road. An effort is being made to target high-risk communities and identify effective community-based organizations, from Hawaii to Brooklyn. Rabbi Edelheit noted that a high-risk population is not the same as high-risk behavior.

Dr. Aranda-Naranjo pointed out how difficult it is to apply outcome indicators to a situation where multiple problems exist, e.g., drug use, mental illness, and spousal abuse all in the same family. These are clients nobody wants, the throwaways. She also noted that not just embarrassment but also economics keeps people from admitting to infection; for instance, the

migrant workers among whom she practices will not get jobs if they admit to infections. Dr. Goosby asked, "What do we say works in situations with those concerns? How do you tease out those areas where improvements are occurring?"

Dr. Levine said she would put a lot of the few dollars that are available into medical schools to teach about HIV and related concerns, not just into those mid-level care providers discussed previously. Dr. Hitt thanked Dr. Goosby for continuing to work in this area with limited staff and resources.

Marion Odubiyi and her Group of Silver Spring, Maryland, Teenage Peer Educators

Dr. Hitt announced the arrival of about 15 high school students from suburban Silver Spring, Maryland. Ms. Odubiyi said that about 11 years earlier she had been introduced to HIV/AIDS through the hemophiliac community and had never left it. She introduced her young people, who she promised would ask some hard-hitting questions. She then mentioned a series of milestones in AIDS, and the equivalent age of her teenagers: In 1991 when Magic Johnson announced he had HIV, most of her students were about 10 years old. By and large, they did not even remember that event.

She declared that those with the responsibility still are not educating young people properly. Youngsters aged 17-19 still do not know about HIV/AIDS. What is happening to improve this? Noreen, a high school student, said college students joined her group to get basic information they lacked. What is the Government doing about this? Also, female condoms are four times as expensive as male condoms—too expensive for disadvantaged females. Kevin, another student, pointed out that existing programs are very limited as to what they can say. People could use a program like the peer educators.

Comments and Questions: Mr. Anderson thanked the students for asking these questions, because they are the same things the Council has been saying. The Council feels an incredible level of frustration right now. He said that about a year earlier the Council had approved a vote of no confidence in the Administration in connection with HIV prevention. The Council is still complaining, but with little change. Mr. Blackwell and Dr. Cade thanked the young people for coming. Rabbi Edelheit said the students should bring HIV/AIDS up with their pastors: Are you ready to preach on this? This is not just a matter of Government. Mr. Fogel said the Federal Government is way too conservative, especially Congress. The young people should get out and vote.

Several other Council members also thanked the young people for coming and noted that their own concerns were similar to those of the students. This included, again, concern that certain issues cannot be discussed in school. Ms. Miramontes said Congress had voted $50 million 2 years ago to advocate only abstinence as a way of avoiding AIDS. Now they are talking about $50 million more for the same purpose. The young people were asked to talk to their Congresspeople during the AIDS walk in early May. Dr. Hitt said the Council had made many

recommendations along the lines the students had asked about. Mr. Summers said that the staff policy position being added to ONAP would be given to a person of color.

Adjournment of General Council Session

Tuesday, March 16, 1999

Additional General Council Session, Tuesday Morning

Dr. Hitt opened the session by saying that the most important issue the Council had to deal with at this time was to discuss what to talk about with Mr. Kevin Thurm, Deputy Secretary of HHS, who was to speak to the Council later the same day. Six issues were of particular importance for this discussion:

1. $10 million "Know Your Status" campaign. The Council wants to ensure a clear understanding between itself, ONAP, CDC, the community, and HHS as to where this money is going. In particular Dr. Hitt wants to clear up any confusion about the $90 million and $10 million of which Mr. Summers spoke yesterday (the $10 million as a demonstration project to test what worked, to be applied to the $90 million).

2. $8 million for the Office of Minority Health—what is going on with that, to get it spent?

3. Surveillance paper.

4. Timeline on HHS strategic plan on HIV/AIDS, in connection with Ryan White reauthorization. Mr. Thurm has to tell the Council where it is going.

5. Health care workers.

6. Needle exchange. HHS has not done enough on dissemination of the science; what will be its legislative strategy this year on needle exchange?

Prevention Subcommittee—Media Campaign: Mr. Isbell said that $10 million for a "Know Your Status" campaign appears in the FY 2000 budget, but that he feels this is not enough for a media campaign. He noted that some parts of the Administration are wondering whether a media campaign is even advisable. The word is that the current plans are to use the $10 million for new and innovative counseling and testing techniques, as a way to figure out how best to use the $90 million in other funding that is available for counseling and testing but that people feel is not being used wisely.

The Subcommittee still believes that a good counseling and testing campaign is needed. The Subcommittee also believes that a rational prevention plan has never happened because of a lack of leadership at the top. The White House needs to become engaged. Marketing is needed to sell HIV testing. A major media campaign is needed around testing. The President supposedly

responded favorably in the December meeting. Council members need to talk to Mr. Thurm about this.

Ms. Thurman agreed that a media campaign is needed. The epidemic is not over, and people need to be tested. These facts represent two very different campaigns. Whatever is done should not merely rehash the past. There were no awards for past ad campaigns in this area. If the $10 million is used for a campaign, it should mean Madison Avenue, a public-private partnership, and a "very heavy lift."

Dr. Hitt asked whether ONAP really wants to do it, and Ms. Thurman answered yes, but with people outside of the "Just Say No" campaign. Mr. Isbell pointed out that testing is a bipartisan good thing. The money should be used not for the actual campaign, but for focus groups, polls, and going to Madison Avenue. Maybe funds could be gotten from the Advertising Council and the pharmaceutical industry. Maybe some Republican Hill support could be obtained. Ms. Thurman said that the Council does not control the money and is therefore hamstrung. But finding out what works, through focus groups and other means, can be done—it *is* done in political campaigns.

Dr. Hitt asked what specifically the Council should discuss with Mr. Thurm. The $10 million available is actually with CDC, but that agency is not communicating its plans to use it over the next 6 months. Mr. Summers said that at least CDC has stopped it from going down the drain. But it has not yet decided how it *will* be used. Dr. Hitt said the Council should make sure that Mr. Thurm tells CDC that this is the direction it should be going in. Mr. Henderson said it would help if staff could bring in a private-sector expert to help with the ad campaign. They should not rely on those who were unsuccessful regarding a public-private partnership.

Ms. Thurman said that CDC makes the decisions and lets the contracts. She does not know how to get out of the box. Rev. Perez said there should be a two- or three-page paper that describes the Council's views, so there will be no misunderstanding.

Dr. Levine said professionals such as the TV Academy do this pro bono, but the Government pays someone else. Should the Council get CDC together with the TV Academy? Ms. Fraser-Howze said that detailed instructions are necessary for the campaign, possibly coming from the Prevention Subcommittee.

Mr. Fogel said it is not a prevention campaign at $10 million. The concept is to do a campaign in concert with the Ad Council, the pharmaceutical industry, and others who have a lot of money. It is important to get people to know their status. This would create a flood of pressure for testing, counseling, and services, and would get the Government to act. But yesterday Mr. Summers spoke of sample tests. This is quite different. Mr. Fogel did not criticize CDC—they never thought of what he was advocating. Testing should be normalized. Mr. Henderson advocated forgetting about the $10 million for now. Instead, a plan should be prepared. Ms. Thurman could convene a meeting of TV people and others, and then they could worry about the $10 million.

Dr. Hitt proposed that members write down their recommendations on a couple of pages. Ms. Thurman could take the recommendations to the right people and get a reply, yes or no. Once

the program is accepted, let those people run it. Ms. Thurman could have a meeting with CDC and the Council to see if they are all on the same page, and the Council can discuss it with Mr. Thurm today.

Service Subcommittee—Access to Care: Mr. Henderson said the Subcommittee had heard from Representative Pelosi's office, HCFA, and the Kaiser Family Foundation about how to expand early access to care. A lot of effort was put into modeling by HCFA, the Kaiser Family Foundation, and others regarding care costs and waivers. So far, only one State—Maine—has applied for a waiver. If Florida or California were to apply, it would make a difference in terms of the total numbers.

He noted that two issues have "built a wall": (1) the parameters of budget neutrality, which made the omnibus bill strategy interesting, because it allows a greater degree of bargaining; and (2) the "elephant in the room," drug pricing. If the Government becomes an even greater purchaser, there has to be some way of dealing with the cost if matters are ever to be brought into balance. How can public or political opinion regarding these two issues be moved? The Council should monitor this but not get too involved. Mr. Abel noted that everybody is waiting to see what happens to the Maine waiver application, or to the expected Massachusetts application. Then the floodgates could open. At least 25 States might ask for a waiver.

Mr. Henderson then noted that, regarding number one above, there is more flexibility and wheeling and dealing in an omnibus-type budget, e.g., what the CBC did, and therefore it was easier to get what they wanted. But dealing with the drug companies regarding number two, pricing, might actually be easier than number one. Dr. Hitt said he feels access to care, or the cost of drugs, is not such a big political issue: larger market, lower prices. Mr. Henderson said the waiver process is sort of on automatic pilot: what can the Council do to *affect* it?

Adjournment of Additional General Council Session

General Council Session, Tuesday Afternoon

Mr. Richard Stafford took this occasion to announce his resignation from the Council for health reasons. He thanked ONAP staffers, fellow Council members, and staff people for all they had done for him. The Council and observers gave Mr. Stafford a standing round of applause.

Kevin Thurm, Deputy Secretary, U.S. Department of Health and Human Services

Dr. Hitt then introduced Mr. Kevin Thurm, Deputy Secretary of HHS, noting that Mr. Thurm had put out his hand to the Council and worked hard to cooperate with it. Mr. Thurm noted that the last time he had spoken with the Council had been over a conference phone call, and it was not such a productive session. He expressed the desire to meet regularly with Council representatives. That way *they* would have an accountability mechanism. If they call they will get answers, even if not always what they want to hear.

In June 1998 the Council identified a short-term agenda: (1) advance the call for a State of Emergency to help African American and Latino communities; and (2) work with CDC and get additional funding for AIDS issues, higher appropriations for HIV/AIDS, and vaccines.

Regarding vaccines, Ms. Thurman announced that Dr. Gary Nabel will be head of the new NIH Vaccine Center. Those involved should do a better job of coordinating resources across the Government, including having NIH people in ONAP. More financial resources will be available through the budget for FY 2000, including across Ryan White. Regarding the safety net initiative, a little over $1 billion in 5 years, HHS will be implementing it, including integrated systems of care on the local level that should provide improved access to care for the working uninsured.

The Council has asked HHS for a strategic plan for prevention. HHS does need a document for accountability. It should be comprehensive, showing where the Government should go, across HHS and the agencies, regarding HIV/AIDS. Regional directors are carrying on a dialogue on HIV and AIDS, particularly on how it affects minorities and women. The strategic plan has to leave tracks—here is where the Government should be going regarding AIDS.

HHS will be working hard on the State waiver issue, and especially on Maine's application, the first request for a waiver. There is the problem of budget neutrality. The agency will learn a lot from this first waiver application, including developing generic principles for evaluating future waiver requests, which should be done by mid-1999. Getting ahead of the curve with OMB regarding the budget is the next big problem.

The HHS Secretary's response letter to Dr. Hitt spoke of the special needs of racial and ethnic minorities, and of CDC's efforts to meet those needs in better and more efficient ways. Also needed are more culturally sensitive and targeted outreach and testing activities for developing linkages for prevention and health care services for the incarcerated who are returning to the community. Such efforts need to be monitored, as do those targeted to communities of color.

The Council has commented on the inconsistency between the HHS commitment to women in Healthy People 2010 and its disparities in comparison with other groups. Changes to the draft are anticipated. Regarding the Interim National Minority HIV Plan, OMH is expected to be sending it forth and HHS will publish it. The $8 million for OMH is in the emergency supplemental, and once that is made law, the $8 million will come through.

Finally, the Council has pointed out correctly what HHS has not done regarding getting out the science on needle exchange. More and better information on this subject can be expected. This discussion is 18 months overdue, and this accountability is needed. Mr. Thurm will be back in June and will be meeting with Subcommittee chairmen bimonthly.

Questions: Mr. Henderson asked about expanded access to care. He noted that earlier Mr. Thurm had said he, Mr. Thurm, would be meeting with OMB regarding waiver parameters. Mr. Thurm said the parties negotiate, including asking the State making the waiver request to explain its proposal. He said HHS has a long history of budget neutrality issues with OMB, but Medicaid 1115 is new.

Dr. Levine asked who would receive the scientific information regarding needle exchanges, and when. And what is the legislative strategy for a Congress that won't be listening? Needle exchange is a focus to help people get *off* drugs, according to some studies. Mr. Thurm replied that the "who" was a lot of people, and asked the Council to make suggestions to HHS as to who should get the information. The timing should be sooner rather than later. HHS and OMB have to work out a legislative strategy, especially regarding when.

Ms. Fraser-Howze commented that the CBC is committed to OMH, but that some quarters see it as a wasteland for the Administration. If the Administration is serious about the disparity between HIV/AIDS rates for minorities and the general population, building up OMH is critically important. Mr. Thurm said that a national search is under way for a director. Both leadership and funding are priorities. His guess is that the emergency supplemental, with the $8 million, will pass; if not, HHS will find another way.

In reply to a question from Mr. Robinson, Mr. Thurm said it is his understanding that CDC would run the "Know Your Status" program. HHS feels it should be run by ONAP, although the money could be administered by CDC. CDC is the place for this. A number of Council members voiced audible disagreement with this last statement.

Mr. Isbell noted, on "Know Your Status," that one thing America knows well is how to *sell*, how to find out attitudes and how to use them to sell, in this case, testing. Rabbi Edelheit said the Council is looking for something fundamentally different, holding ONAP responsible. Mr. Thurm stated he believes that none of the CDC money is going for administrative purposes, but Mr. Robinson said people had explicitly told him that $1.5 million is for administration, perhaps a miscommunication. Mr. Thurm asked Mr. Robinson to send him, Mr. Thurm, a note and he will try to get an answer.

Dr. Nilsa Gutierrez stated that Puerto Rico has a very high infection rate. Could Medicaid provide funding to deal with this crisis? On the international side, the United States recognizes the needs of areas like Africa and Southeast Asia, but Mexico also has a serious problem. Mr. Thurm said he did not know the answer but would check it out.

Mr. Stafford asked how they could bring all of this together—not just this or that department. Mr. Thurm said the Council had helped set the agenda, and the Administration is indeed focused on care, vaccine, and minorities. There is an effort to get people together (e.g, HCFA, CDC, and others) to see what has been learned so far regarding prevention, care, and other matters.

General Discussion—Council Member Terms: Dr. Hitt returned to the question of terms for Council members. He pointed out that probably all Presidential councils had term limits of 4 years. He asked whether the HIV/AIDS Council could be made smaller. He noted that the White House Personnel Office decided what a council should look like, what it could do, and so forth. The Administration is concerned about AIDS. He reaffirmed that current members can serve until they are replaced, and noted that it takes a long time to fill vacancies. He asked those who want to leave, and perhaps have been less active on the Council than some others, to let him know their wishes. He stated his desire that the Council set a time to discuss whether it should be reduced or

enlarged. When one Council member said that he for one would like to stay on the Council, Dr. Hitt said that it is very difficult to reappoint current members of such councils.

Medical Update: Dr. Hitt then gave a medical update. He pointed to the March 1999 issue of *Esquire* magazine, which provides a dark view of the immediate future regarding HIV/AIDS cures or remedies. He said things are not as bad as *Esquire* painted them. He believes the death rate will level out, since about 50,000 people a year get infected. Lots of people get AIDS. This has long-term implications, e.g., regarding costs. Of the HIV-infected, one-third do not even know it, one-third get the wrong treatment, and one-third are compliant with what they need. Given the currently available medications, the odds are good that those in the last third who are just now starting on medications have a very good life expectancy. But half the victims have already taken sequential drugs. These drugs are wearing off because of virus mutations, a condition shared by many people around this table. If we don't do something, we are in trouble.

HIV Life Cycle: Dr. Levine spoke about the life cycle of HIV. A part of HIV is a perfect fit for the CD4 cell receptors. A new product called T20 prevents the docking with the second receptor. People without the second receptor apparently cannot be infected with HIV—prostitutes in Nairobi have been exposed forever and have not contracted the disease. One can be infected, but the disease is different: long-term nonprogressors.

The HIV's RNA becomes the DNA of a human being and inserts itself into the T4 cell. HIV can be silent in that cell as long as there is no exposure to something foreign, e.g., smoke. HIV kills T4 cells, and the body makes up for them—for a while. The T4 cells control the immune system. AZT prevents viral RNA from becoming DNA. But if it has already become DNA, the virus can hide there as part of the DNA. So this kind of medication can never cure the infection.

Dr. Levine noted that AZT works for only a year or so. The next step is possible combinations of drugs. Clinicians never use only one drug in cancer because the cancer learns to live with it. At first there was only one drug for HIV, AZT. But as soon as there were more drugs, physicians started combining them. The real issue is the protease inhibitor. Protease inhibitors are more powerful and can take an infected cell and stop it from reproducing. Now medicines could attack HIV from different angles, and the question arose: Could this illness be curable?

Dr. David Ho at one time said he thought all infected cells would die within 3 years. But now it is known that some cells can live 20-25 years, not just 3. So the concept of cure becomes difficult. And there are the very difficult side effects. Forty pills a day for life: no one can do this. There is also the potential of contracting diabetes or lipodystrophy, the addition of significant body fat while the limbs become much thinner. But there are new drugs, T20 and integrase inhibitors. HIV/AIDS is a chronic disease.

Therapy: Dr. Hitt stated that four significant questions need to be addressed:

1. When do you start therapy?
2. What do you start with?
3. When do you switch?
4. What do you switch to?

Often, because the virus can mutate so easily, early therapy may be worse than none and result in a decrease in the quality of life. He noted that the patient has to be ready, in the psychological sense, to enter such a tough drug regimen. There can be severe side effects. This may require cutting back or even stopping therapy for a while. Patients should be careful of the claims of drug makers—their statistics may be incorrectly analyzed, to their advantage. Promising combinations are being found, however, and the complexity of 40 pills a day appears to be going away.

Then there is the cost of saving a year of life, only $18,000 per year for triple therapy, compared with $18 million for saving a life from earthquakes. If a person is getting severe side effects, he or she should stop the drug and see what happens—maybe the numbers will only very slowly go bad, and the patient can always start up with drugs again if that happens. Mr. Landau asked whether HIV could actually stimulate the immune system in certain cases, and Dr. Levine said that certain symptoms like sweating are in fact the result of the immune system's fighting back.

Subcommitee Reports

Research Subcommittee: Dr. Levine said her committee's only new recommendation was to repeal a rider to the Omnibus Appropriations bill passed late last year. This rider allowed individuals and organizations to use the Freedom of Information Act (FOIA) to acquire access to raw research data if the project was funded by a Federal grant. This could result in the misuse of inaccurate, only partial, research data; the potential loss of subject confidentiality; the potential loss of time to researchers who would have to expend time and effort to comply with the law; and other problems. Representative George Brown, the ranking minority member of the House Science Committee, introduced H.R. 88 to repeal this provision. The Research Committee recommended that the Council urge the President to support H.R. 88 and to help support a similar repeal bill in the Senate.

Mr. Summers, of ONAP, explained that this bill actually originated in problems relating to research supported by the Department of Energy, but it could have a serious effect on biomedical research. FOIA is a leaky vessel, not meant for the kind of information one finds in biomedical research. Dr. Hitt suggested that the Council should send individual letters or express itself as a whole. He then proposed that the Executive Committee write a letter in the name of the Council. The Council voted "aye" unanimously.

Dr. Levine also advocated the restoration of $15 million to the budget of the Department of Defense for its HIV/AIDS research, more than half of which is devoted to vaccines. She said she and her colleagues had already written a letter from the Council. The money was cut out of the FY 1999 budget at the last moment, and the Administration asked for the equivalent lower figure for FY 2000. There is a second issue of behavior's changing in the wrong direction. Why is this? Research is needed on why, including the positive effect of peer counseling.

Racial and Ethnic Populations Subcommittee: Rev. Altagracia Perez asked what the strategic plan is for the CDC funds. The Subcommittee has gathered information from all the other subcommittees that is relevant to its work, e.g., regarding American Indians. Subcommittee members have to find out who the strategic persons are to whom they can speak to build

accountability. They may have an interim meeting before June. Dr. Hitt thought such a meeting is a good idea if everyone is available.

Prevention Subcommittee: Mr. Robinson said his group had received CDC's report on the current situation of the "Know Your Status" campaign. There is nothing inconsistent between CDC's plan and what the Subcommittee has proposed. The Subcommittee did make it very clear to Mr. Thurm that it thought the program should be administered by ONAP. The Subcommittee was pleased by CDC's overall strategy and the comprehensive way its staff are thinking about the issue. On surveillance guidance, few changes were made in the document sent by CDC to HHS. There will be some changes and the Subcommittee wants to stay informed. Dr. Hitt said he thought that in dealing with Mr. Thurm on such issues, if the Council prepared 10 or 12 questions a week before meetings with Mr. Thurm, they would likely get good answers from him.

Services Subcommittee: Mr. Henderson described the bills introduced by Representative Nancy Pelosi and 59 consponsors, and Senator Robert Torricelli, to allow low-income HIV-positive but not yet overtly AIDS-suffering people to receive Medicaid. Ms. Pelosi's staff suggested, and the Subcommittee agreed, that the Council should write a letter to add its weight to the forces behind these bills and help increase the number of cosponsors. Extension of the Medicaid entitlement would help to institutionalize, and thus make permanent, this new funding for HIV.

Dr. Hitt stated that ordinarily the Council does not endorse legislation at such an early stage in its development. The Council should perhaps wait until the bills pass their respective chambers and are at the conference committee stage. He asked whether some good people might refuse to endorse this change in Medicaid, and if they did refuse, why—the bills should be vetted.

Dr. Aranda-Naranjo said that such bills help elevate the issue. They are complementary measures, not alternatives, to the State waivers discussed earlier that would allow the States to provide Medicaid help to HIV-positive people. With such a law in effect, there is no need to find an offset in the budget. Mr. Henderson said the legislation would lessen barriers for the States; it would represent a kind of preapproval by Congress. Mr. Robinson said he had some of the same questions as Dr. Hitt. The Council could educate some of the Republicans in the House to what this would mean for some HIV-positive people. Are there any costs to the legislation? Would the financial costs have to be offset? What are the political dynamics?

It was suggested that the Council send a letter endorsing the objectives of the bill but with an escape hatch if the bill should be sharply mutated in a way the Council could not accept. Dr. Hitt suggested that the Executive Committee deal with any endorsement. This idea passed unanimously.

Appropriations Subcommittee: Ms. Aragon said the Subcommittee received briefings from several people the day before about the Ryan White CARE Act reauthorization. It is not likely to occur before the end of 1999 or early 2000, as the current authorization does not end until September 2000. But because of the political volatility of AIDS issues in the Congress at times, it is important for the AIDS organizations community to come to a consensus as soon as possible on what changes have to be made. There may be some administrative changes, but none in the legislation.

One negative likely to come up in a debate is the threat of mandatory testing, names reporting, and partner notification. Also, the National Governors Association has spoken about the possibility of block grants to the States, instead of money going directly to cities or to community organizations, as is now the case. HRSA is looking at how well the CARE Act serves certain populations.

Mr. Charles Blackwell mentioned National Organizations Responding to AIDS (NORA) as a major Ryan White advocacy group.

Mr. Henderson discussed the Jeffords-Kennedy bill. It has 67 cosponsors in the Senate and excellent prospects in the House as well. It includes $300 million for demonstration programs for States, over 5 years, to allow people with diseases to go back to work without losing their Medicaid coverage. To put this in context, it should be noted that the Kaiser Family Foundation estimates that HIV-infected people alone need $1.3 billion of this kind of support over 5 years. Mr. Anderson said giving people without insurance access to Medicaid even if they go back to work would lessen their fear of doing so.

International Subcommittee: Mr. Anderson said the Subcommittee was frustrated with the U.S. commitment, or lack thereof, to the international aspects of stopping HIV/AIDS. It would like to have at least some members of the Council meet directly with Frank Loy, Under Secretary of State for Global Issues, before the next Council meeting. On the other hand, under the World Trade Organization, there is also a danger that U.S. firms could be forced to license for a fee their medicines to overseas companies for production in those companies' countries—at very low cost. The International Subcommittee wants to have a debate before it between advocates of both sides of this issue, ensuring that the developing world is represented along with the domestic side.

Ad Hoc Committee on Prisons: Dr. Hitt announced that Mr. Jeremy Landau will be taking off part-time from being Committee Chairman and Ms. Judith Billings will be helping out as Co-Chair. Mr. Landau said that Dr. Kendig, the new Medical Officer of the Federal Bureau of Prisons, is a good man from the standpoint of the Council. He noted CDC is putting together an RFP of $7-8 million on standards of care in prisons and linkages and transitions to the community. This will apply to 10 States and metropolitan areas.

Ms. Billings mentioned that the Committee representative had recently met with Dr. Kendig and believed they learned more in an hour with him than they had learned in the past 2 years. Because of H.R. 2070 there is now mandatory testing of prisoners when they enter prison for more than 6 months and meet a certain set of risk factors (testing is voluntary for the others).

One percent of the prison population is now HIV positive, about 1,100 individuals. About 700-750 are currently in treatment (the prisoners can choose to receive treatment or not). The number of deaths is going down, from 57 in 1995 to 19 in 1998, with more deaths in 1998, 25, from hepatitis C than from AIDS. Telemedicine could be of help, especially for prisons in rural areas. Continuity of care and the need for discharge planning are additional issues. As of 1998, 73 percent of prisoners in drug treatment programs were less likely to be rearrested than those not in treatment, and 44 percent were less likely to relapse into drug use.

After thanking Mr. Montoya for doing the work of three or four people, Dr. Hitt adjourned the Twelfth Meeting of PACHA.

Adjournment of General Council Session