

**Presidential Advisory Council on HIV/AIDS  
Seventh Full Council Meeting**

July 25–26, 1997

Wyndham Garden Hotel  
Atlanta, Georgia

**MINUTES**

**Present:** R. Scott Hitt, M.D., Chair; Stephen N. Abel, D.D.S.; Terje Anderson; Regina Aragon; Judith Billings; Mary Boland; Nicholas Bollman; Jerry Cade, M.D.; Rabbi Joseph A. Edelheit; Robert Fogel; Debra Fraser-Howze; Kathleen Gerus; Nilsa Gutierrez, M.D.; Robert Hattoy; B. Thomas Henderson; Michael Isbell; Ronald Johnson; Alexandra Mary Levine, M.D.; Steve Lew; Helen H. Miramontes; Robert Michael Rankin, M.D.; H. Alexander Robinson; Debbie Runions; Sean Sasser; Benjamin Schatz; Richard W. Stafford; Denise Stokes; Charles Quincy Troupe; and Bruce Weniger, M.D. Also present were Sandra Thurman, Director, Office of National AIDS Policy (ONAP); Daniel Montoya, Executive Director for the Presidential Advisory Council on HIV/AIDS (PACHA) within ONAP; Todd Summers, Deputy Director, ONAP; and Paul Yondura, Special Assistant for the Department of Housing and Urban Development (HUD) and Agency Representative to ONAP.

**Absent:** Tonio Burgos, Phyllis Greenberger, Jeremy Landau (participated in Prison Committee meetings via conference call), and Rev. Altagracia Perez.

**Opening and General Council Business**

Dr. Hitt, Chair, opened the Seventh Meeting of the Presidential Advisory Council on HIV/AIDS with a review of the agenda and report on interim activities. Mr. Montoya was commended for his “double duty” as PACHA Executive Director and interim Deputy Director of ONAP, and Mr. Yondura was recognized for his assistance with PACHA activities within ONAP.

**New Council Members:** Dr. Hitt introduced and welcomed Nilsa Gutierrez, M.D., M.P.H., primary care delivery systems consultant from Teaneck, New Jersey, and Sean Sasser, Media Resource Center Manager, Gay and Lesbian Alliance Against Defamation (GLAAD), Atlanta.

**Goals of the Meeting:**

- Assessment of responses to PACHA Recommendations by Committees
- Increase in Council knowledge of and prioritization of prevention issues

- Establishment of a “watchdog group” to begin meeting within the next few weeks by conference calls to determine appropriate actions and timing for PACHA Recommendations regarding national budget issues
- Development of PACHA’s 1997 Progress Report
- Finalization of an interim letter to the President regarding response to Recommendations to date

**Public Demonstrations:** The opening session was interrupted by members of ACTUP San Francisco who demonstrated before the Council, with the basic messages that AZT and other chemotherapy treatments are toxic to AIDS patients; HIV does not cause AIDS; pharmaceutical companies are more interested in making money than helping AIDS victims; PACHA and ONAP are not knowledgeable about HIV/AIDS and do not care; use of condoms must be promoted, and manufacturers should help pay for dissemination, especially among poor, young people; animal research is invalid; and billions of taxpayers’ money being spent on unrealistic research should go to clinical research and providing sick people with housing and other day-to-day necessities. Individuals were given an opportunity to verbalize issues, and they called on PACHA and ONAP to bring these messages to the Federal Government.

As the demonstrators posed some physical threat to Council and ONAP members and their property, Atlanta police were called and provided security for the remainder of the meeting. In discussing the demonstration later, Council members agreed with some concerns; however, Mr. Hattoy noted that the indicted medications have proven highly beneficial to HIV/AIDS victims, as has animal research. Ms. Miramontes said she was angered by the remarks, which show that demonstrators do not respect Council members’ long involvement with and knowledge of AIDS. Mr. Schatz did note that this group does not represent the national ACTUP organization.

The President of Animal Abuse Watch, Sue McCrosky, came to speak against the use of monkeys in HIV research, but Dr. Hitt suggested that she present her concerns to PACHA’s Research Committee.

**Prevention Committee Meeting with CDC:** Feedback was given on an informational discussion session hosted by the Centers for Disease Control and Prevention (CDC) and Dr. Helen Gayle, Director of the CDC’s consolidated HIV/AIDS research group, on July 23–24, for the Prevention Committee and other interested Council members. PACHA members present included Mr. Robinson, Dr. Abel, Mr. Anderson, Ms. Billings, Dr. Cade, Mr. Fogel, Ms. Gerus, Mr. Hattoy, Mr. Henderson, Dr. Hitt, Mr. Isbell, Mr. Lew, Ms. Miramontes, Ms. Runions, Mr. Schatz, and Dr. Weniger. Ms. Thurman and Mr. Montoya attended from ONAP.

Mr. Robinson reported that discussions were highly informative and that, in response to PACHA’s written questions about its prevention program, the CDC had prepared a complete briefing book on HIV/AIDS activities. A number of CDC staff members also participated in the PACHA Council meeting and Committee sessions. Dr. Hitt thanked the CDC and Mr. Robinson

and Mr. Isbell for putting together a meaningful meeting, with assistance from Mr. Montoya. Members interested in receiving a copy of the briefing book should contact Mr. Montoya.

**PACHA Issues and the DHHS:** Concern was raised over several PACHA issues that have not been addressed by the Department of Health and Human Services (DHHS), and the Council agreed that a plan is needed to have those issues resolved. One issue that became very clear during the meeting with the CDC, Mr. Isbell said, is the lack of progress being made on needle exchange programs. The Council should aggressively seek some resolution on this urgent prevention issue through a meeting with DHHS Secretary Donna Shalala, a formal letter to the Department with copies to other agencies and the Administration, and/or other methods.

### **Office of National AIDS Policy Update**

Ms. Thurman reported on Administration response to the Council's Recommendations and critiques of the national AIDS program and on activities and staffing of the new ONAP office since her appointment to the directorship in April.

**AIDS Vaccine Update:** The President's announcement at Tuskegee University on May 18 that the United States is focused on development of a vaccine within the next 10 years was in direct response to a PACHA Recommendation. The surprise announcement left ONAP little time to do a proper "rollout"; however, press coverage has been good, especially internationally. Further, NIH is actively seeking a national director for vaccine research, with Dr. Harold Varmus, Director of NIH, heading the effort and Dr. David Baltimore, Chair of the NIH AIDS Vaccine Research Committee (AVRC), advising.

**AIDS Vaccine Initiative:** A Call for HIV Vaccine Development was initiated during the G-7 Summit in Denver on June 20 by the International AIDS Vaccine Initiative (IAVI), with more than 60 of the world's leading AIDS-related, nongovernmental organizations signing the document. It asked large, industrialized nations to devote new resources to the effort, with assurance that vaccines are produced for developing countries, incentives are created for maximum participation of the pharmaceutical/vaccine industry, and agreement is reached on specific mechanisms to ensure mutual cooperation and coordination. The initiative also asks that funds not be diverted from research into therapeutics and prevention and that new financing mechanisms, such as an AIDS Vaccine Development Fund and AIDS Vaccine Purchase Fund, be considered. Again, press coverage has been better in foreign countries than in the United States, where immunization is routine. ONAP since has had talks with pharmaceutical companies about cooperation and has seen good support from both gay and scientific communities. Conversations and collaborations with international researchers must be involved in vaccine development and suggested that PACHA take a major role in this area.

**FY 1998 Budget:** In its first round of talks, Congress made the following recommendations for AIDS funding increases: CDC prevention, \$5 million (House)/\$30 million (Senate); Ryan White programs, \$172 million; AIDS Drug Assistance Program (ADAP) funding, \$81million (House)/\$50 million (Senate); NIH programs, \$73 million (House)/\$112 million (Senate). "The President asked us to focus on the higher numbers," Ms. Thurman said, and is "fighting to hold

them.” Asked whether certain NIH allocations of AIDS funding was new money, she said that the sum in question (\$17 million) was not diverted from other AIDS programs.

**Needle Exchange:** This issue is more problematic, and ONAP is working intensively following release of a Federal report that needle exchange does decrease HIV transmission without increasing drug abuse. Several high-level agency meetings have been held, with Mr. Robinson representing PACHA. DHHS has briefed the White House on where it stands on needle exchange and has been asked to develop an action schedule immediately. ONAP has met with General Barry R. McCaffrey, Director, Office of National Drug Control Policy, with Dr. Gayle and Dr. Varmus in attendance to address the science of the issue of needle exchange. Asked about the President’s views on needle exchange, Ms. Thurman said that he wants to protect the Secretary (Shalala) and preserve DHHS authority. It was noted that there is growing frustration about where this Administration is going and that needle exchange is a litmus test for its commitment to AIDS.

**President’s Update on AIDS:** Ms. Thurman has good access to the President, sending him weekly update memos—to which he often responds with handwritten notes—and seeing him when she needs to. She had briefed Mr. Clinton just prior to the PACHA meeting and said that he was stunned to hear of the perception in the AIDS community that the White House has deemphasized the disease. Critical issues such as needle exchange, new Public Health Service (PHS) Guidelines to Standards of Care, ADAP funding, and Medicaid expansion were discussed, although there was insufficient time to cover discriminatory practices within agencies. Mr. Clinton had received PACHA’s letter on discrimination, and ONAP has contacted the agencies for a status report on these policies. Ms. Thurman said she believes the President sees PACHA letters and recommendations and passes them on to appropriate staff (such as Bruce Reed, Assistant to the President for Domestic Policy) to handle. Addressing Council concerns as to whether he actually hears PACHA messages, she said that he gets the information and understands it.

Dr. Hitt said that most Council members want to be supportive of the White House but have become skeptical since so little has happened. Mr. Robenson said that the most critical concern is needle exchange and urged that ONAP help facilitate a meeting with the DHHS Secretary as soon as possible. Ms. Thurman encouraged the Council to conduct the same conversation with the White House.

**Medicaid Expansion:** Expansion of Medicaid to include People Living with HIV/AIDS has been called “much more complicated than originally thought” by the Health Care Financing Administration (HCFA), which told the Vice President that it will revise its proposal within the next few weeks. Mr. Lew noted that DHHS could get input from States, where some creative things are being done in this area. The Services Committee is concerned that funds needed for Medicaid expansion will be taken from other necessary programs such as Supplemental Security Income.

**ONAP Organizational Chart/PACHA Role:** Ms. Thurman presented a draft organizational chart of ONAP and how it relates with the President and PACHA, saying that this arrangement and PACHA’s support lets ONAP operate in a way that it could not do as effectively otherwise.

Council members asked Ms. Thurman for clarification as to its direct accessibility to the President, and she said that the chart would be modified to show these relationships.

**ONAP Staffing:** Staffing has been slow, and members voiced concern that the office has not received sufficient support in this area. They believe that PACHA Recommendations cannot move forward without better staffing within ONAP. The situation is improving with incoming Deputy Director Todd Summers and Mr. Yondura on detail from HUD to help with PACHA activities and reorganization of interagency work on AIDS. Mr. Montoya said that Dr. Eric Goosby, Director of the Office of AIDS at DHHS and former acting director of ONAP, is able to provide some assistance, although not as much as had been promised by DHHS.

**Other Activities:** Future activities under consideration at ONAP include:

- The possibility of hosting White House leadership conferences on women's issues—making AIDS an issue for women leaders in U.S. Government, business, health care, and policy—and on people of color. Dr. Levine, noting that the death rate from HIV has increased in women while decreasing in other populations, asked if this is an issue that the President is aware of; Ms. Thurman said it is.
- Major participation in World AIDS Day, during which ONAP has opportunity to address both children's and international issues. Ms. Thurman asked PACHA members for suggestions on ONAP's first-ever participation in this event.
- Back-to-work issues, on which "something will happen by Christmas." Mr. Johnson said that these issues carry assumptions that may not be correct and improvements in vocational rehabilitation and training must be included in any recommendation.

Dr. Weniger thanked Ms. Thurman for her leadership, saying that the Council is pleased with the President's announcement on the vaccine initiative within her first 6 weeks in office and with having direct feedback on Mr. Clinton's reactions to its Recommendations and concerns. Dr. Hitt also thanked Ms. Thurman and pledged PACHA's continuing support to ONAP. "It is in our best interest to have ONAP as strong and as autonomous as possible," he said.

### **Committee Meetings, Reports, and Action Plans**

Committees and Subcommittees convened on July 26 and 27 to address a Council charge to assess Administration response to Recommendations, list and prioritize uncompleted Recommendations, develop plans of action, and set up future conference call schedules.

#### **Research Committee**

Members present were Dr. Levine, Chair, Mr. Hattoy, Dr. Hitt, Mr. Johnson, Ms. Miramontes, and Dr. Weniger. Also present were Ray Greek, M.D., Medical Research Modernization Committee; and Upham Garance, SID Alert, who reviewed AIDS research concerns and activities involving South Africa.

**General Assessment:** Dr. Levine said that there have been positive commitments made by the Administration on such issues as microbicides and women and children in clinical trials. The words have been helpful, and the press has supported PACHA's priority of vaccine development; the problem is implementation. There is no mechanism to implement a coordinated collaboration. The issue of microbicides has been discussed by the President, but nothing has happened. New funding requested by PACHA has not been found, and only a small (\$2 million) increase has been allotted to the CDC program. The Council needs to organize a plan to help the Administration implement and coordinate development of a vaccine.

**Vaccine Recommendation Action Plan** (to be completed by 10/1/97):

1. Have conference calls with IAVI, CDC, Department of Defense (DoD), United Nations Programme on AIDS (UNAIDS), and some non-Government vaccine researchers.

Purposes: receive feedback on April 1997 Recommendations, ascertain their impact, and determine the next steps for the Council.

2. Conduct private dialogues with Dr. William Paul, Director, Office of AIDS Research (OAR), by telephone, conference call, and/or personally.

Purposes: expand NIH's role in vaccine development; ascertain the status of the new Vaccine Center; determine whether the Center will control the whole \$150 million (in AIDS research funding); explain the Center's relationship to OAR and the National Institute of Allergies and Infectious Diseases (NIAID); and find out where study sections will be located.

3. Have dialogue with Dr. Baltimore via conference call.

Purpose: discuss the AVRC's role and its relationship to the new Vaccine Center.

4. Urge the Vice President, along with Ms. Thurman, to meet with biotech firms, including Merck, Wyeth, SmithKline, Pasteur, Vaxgen, Chiron, Therion, Acrogen, and Virus Research Institute.

5. Draft a document with key issues for main summary and future plans; include rationale, clarification, assessment of effort, highlighting gaps, and future steps.

**Discrimination Committee**

Members present were Mr. Schatz, Chair, Ms. Gerus, Mr. Henderson, and Mr. Johnson.

**General Assessment:** Overall, the assessment is inferior; essentially, there has been no Administration reaction and no improvement. A Recommendation that the President speak out on discrimination has been followed to some extent, but this by-and-large has excluded the military,

and there has been little progress in all other areas, except Americorps, which Mr. Hattoy said has been fixed. An update on the immigration issue by Mr. Lew also points to a lack of progress.

### **Action Plan:**

1. The President should be informed by Ms. Thurman that the policy of mandatory testing and exclusion by the Federal Government continues and that the Council is dismayed. Mr. Reed should be asked by Ms. Thurman or Dr. Hitt to arrange a high-level meeting of the heads of agencies with discriminatory policies. Agency leaders ideally should be told to change these discriminatory policies.
2. The HIV-positive health care worker issue must be on the agenda for a meeting with Secretary Shalala.
3. The Committee asks that Mr. Montoya set up a meeting with the new Justice Department Civil Rights Chief to discuss strong enforcement of the Americans with Disabilities Act and to support dedicated staffing in the ONAP office.

High-level meetings on discriminatory issues, Dr. Hitt said, should be coordinated with other AIDS groups such as gay organizations. He suggested that conference calls be made by the Committee to other groups asking them to put this on their agendas; Mr. Schatz, however, believed that this is a long and complicated way of getting gay and lesbian activists to address these issues. The Subcommittee, he said, is very understaffed and cannot handle all of these actions. Dr. Hitt noted that Mr. Montoya now will have more time to help coordinate such efforts within PACHA Committees.

### **Prison Issues Subcommittee**

Members present were Mr. Landau (via conference call), Chair, Dr. Abel, Dr. Cade, and Dr. Rankin. Also present were Mr. Yondura and John Miles, Special Assistant for Corrections and Substance Abuse, CDC. In Mr. Landau's absence, Dr. Abel presented a written report from the Chair, including response documents from Kathleen M. Hawk, Director, Federal Bureau of Prisons (FBOP) covering PACHA Recommendations on compassionate release, discharge planning, standards of care, protective barriers, and substance abuse and a report from the Attorney General on compassionate release recommendations from the American Bar Association.

**General Interim Assessment:** Analysis and development of Recommendations are complicated by the many strata which exist in the correctional system; thus, much of the attention is focused on the Federal system, which represents less than 10 percent of all inmates. Assessment is difficult because the various prison systems have different methods of collecting and reporting data and testing prisoners, with the latest figures being from a 1994 update. Response from the Justice Department is timely; from DHHS, it is incomplete and in need of further dialogue; and from the FBOP, it is exceptionally slow and, to date, unsatisfactory. Responses are not totally realistic in that the FBOP denies the need for protective barriers among incarcerated individuals, does not think that a revision of the current process for a compassionate release is necessary, and believes

that it is in control of case management, with which the prison community does not agree. Although the FBOP has agreed to work with the DHHS standards of care, the information from that agency is not yet adequate to meet PACHA Recommendations.

**Action Plan:**

1. Very recent response to April Recommendation that requires the Subcommittee to confer regularly over the next months.
2. Conference call planned with Dr. Moritsugu on July 29 to address unanswered Recommendations of December 1996.
3. Prison site visit, along with meeting with community groups (e.g., NORA Working Group on Incarcerated Populations) to address other issues such as women with AIDS, psychosocial counseling, education and training, and clinical trials.
4. Meeting with Health Resources and Services Administration (HRSA) for discharge planning models for prisoners and utilization of AETC.
5. Meeting with Attorney General Janet Reno, if obstacles to obtaining timely information continue.
6. Consideration for Summit Meeting on AIDS in Prison with interagency Federal, State, and community representation. If not a summit, then a request that ONAP bring together key players for open discussion.
7. Reintegration of key issues back into appropriate (PACHA) Committees.

The Subcommittee sees outsiders as helpful in its efforts, including the CDC's prison point person, Mr. Miles. PACHA lost its liaison at HRSA when Patricia Milon left, and the Subcommittee urges ONAP to help establish an appropriate new contact.

**Prevention Committee**

Members present were Mr. Robinson, Chair, Mr. Anderson, Ms. Billings, Mr. Fogel, Ms. Gerus, Mr. Isbell, Ms. Runions, and Mr. Sasser. Karen Mack, M.D., CDC epidemiologist, also was present. In his report, Mr. Robinson said that the consensus is that prevention has been underattended globally, including by this Council, the Administration, and the AIDS community. A more formal assessment was made based on the Committee's meeting in Atlanta with the CDC:

- Despite the President's stated goal of reducing the number of new infections until there are none, there is no plan to achieve that objective
- Prevention is complex, is difficult, and has not been understood. It has received insufficient resources and attention.

- Drug use continues to drive the front end of the multiple epidemics in the Nation; however, the Administration continues to devote more resources to addressing it as a crime and has done little to respond to the Council's Recommendations for comprehensive drug treatment. Of particular concern is that the easiest of the Recommendations—lifting the ban on use of Federal funds for needle exchange—has yet to be accomplished.
- This failure has had a severe impact on women. Although researchers have begun to learn more about the AIDS epidemic among women, few models have been developed for reaching women and few programmatic resources devoted to effective interventions.
- The White House issued a report on the growing epidemic among the Nation's youth, but leadership is lacking to develop comprehensive efforts to save this valuable resource.
- Homophobic concerns continue to encumber the development of scientifically sound prevention research and interventions for gay men.
- The Committee supports the President in his effort to engage the Nation in a discussion about the racial divisions which continue to plague our society. Nowhere has the disparity of this division been more evident than in our inability to stem the tide of new infections among people of color. Here, too, the response has been timid; politics, not science, have guided efforts.
- The CDC has no effective way of tracking the number of infections per year; without population-based surveillance, it is impossible to obtain accurate information. Decisions and resource allotment are not based on good information.
- The Committee is encouraged by the leadership of Dr. Gayle and has a strong sense of optimism about the CDC; yet the agency continues to be hampered by political constraints.
- The CDC must have the ability to lead, and leadership must be guided by the best scientific knowledge.
- The CDC has been involved in this epidemic longer than any other agency, yet its efforts are behind the curve. As evidence of this, the CDC has failed to adequately address the issue of accountability. The CDC must provide greater direction to community planning to target scarce resources to populations with the greatest needs. The CDC seldom uses its authority to ensure that funds are appropriately targeted.
- There is mounting evidence that some efforts by the CDC to provide scientifically based, innovative leadership have been thwarted by political indecision on the part of DHHS. This cannot continue if progress is to be made on the President's goal.

**Action Plan:**

- The ability to track the epidemic is being lost. The loss of any population-based surveillance and the changes in AIDS care require an immediate reassessment of the Nation's surveillance systems.
- A plan must be developed for tracking the epidemic that includes ethnographic, behavioral, and epidemiologic research, a plan that is flexible and permits a dynamic response to the epidemic.

## **Services Committee**

Members present were Mr. Bollman, Chair, Ms. Aragon, Rabbi Edelheit, Mr. Henderson, Mr. Lew, and Mr. Stafford. Mark King, Director of Education and Communications, AID Atlanta, also was present. Mr. Bollman said that the Committee assessed 32 Recommendations, narrowing these to four priorities for action.

**General Assessment:** On certain issues there have been substantial amounts of ambiguous language and action, particularly where so many agencies are responsible, so many funding streams are available, and the health care system and therapies are changing so much. This leaves the committee concerned as to whether anything is being done. In Medicaid expansion, there is an opportunity to include people with HIV, but no policy work has been done on feasibility. Mr. Bollman met with the Vice President's staff, who are frustrated with DHHS failures in all Medicaid issues. Governors are as important as the President in this issue because of the role of States in the program.

### **Action Plan** (with Recommendation areas prioritized):

1. **Medicaid expansion** (lead, Mr. Bollman)
  - Coordinate effort (with ONAP, AIDS Action Council, others) to secure release of DHHS feasibility report, perhaps involving a meeting with Secretary Shalala.
  - Direct engagement with the Vice President and his staff on this issue.
  - Determine an appropriate and effective PACHA approach to States to encourage choosing the expansion option.
2. **Cost of pharmaceuticals** (lead, Mr. Lew)
  - Status report from HRSA, updating the April HRSA response to December Recommendations (addresses various bulk purchase and negotiated price strategies).
  - Status report of Federal Acquisition Streamlining Act (FASA) legislation.
  - Status report from National Alliance of State and Territorial AIDS Directors (NASTAD).

- Followup with the Vice President's office on other pharmaceutical reduction strategies, such as cost of production and profit margins to reasonable levels.
- Consult treatment advocates during Service Committee conference calls.

3. **Managed care/quality-of-care outcomes for people with HIV/AIDS** (lead, Mr. Bollman)

A White House task force including Richard Sorian, Deputy Director of the White House Advisory Council on Consumer Protection and Quality in Health Care, will review care in prisons, the Department of Veterans Affairs, and private managed care and make more specific Recommendations; PACHA will see that HIV issues are covered.

- Review draft report of White House Task Force.
- Prior to that, ask Task Force E.D. or Mr. Sorian and Task Force member Dr. Sandra Hernandez to give the Committee a preview during a conference call.

4. **Keystone dialogue** (leads, Mr. Anderson, Mr. Bollman, and Mr. Lew)

A meeting to determine the feasibility of a Keystone conference will be held August 7, with Mr. Bollman, Mr. Anderson, and Mr. Lew representing PACHA.

- Attend August 7 meeting; then determine further action.

5. **Transition to employment** (lead, Rabbi Edelheit)

- Request conference call discussion with leaders of working groups formed from the New York "Return to Work" meeting.
- Request informal meeting with Department of Labor Secretary Alexis Herman to discuss opportunities to make employment and training and placement funds available to people with HIV/AIDS able to work (funds such as Vocational Rehabilitation, Joint Training Partnership Act, proposed Employment and Training block grant funds).

**Other Upcoming Issues:**

1. Begin to address FY 1999 budget issues (at December meeting) and the President's State of the Nation address.

2. Mr. Summers will prepare a memo on AIDS housing issues and opportunities, to be discussed during a Services Committee conference call.

Asked about AIDS housing, Mr. Bollman said that this is a budget issue dealing with Housing of People With AIDS (HOPWA) and is under Leadership, where it should be a top priority.

Mr. Yondura said that HUD Secretary Andrew Cuomo has pledged to take up this dialog with AIDS organizations and to make AIDS a consideration in all HUD programs and decisions. Ms. Aragon, however, pointed out that Secretary Cuomo twice has canceled meetings with PACHA.

### **International Subcommittee**

The Subcommittee did not meet during this PACHA session; however, Mr. Fogel reported on items of international interest:

- The IAVE is having major repercussions around the world.
- The possibility that UNAIDS would reduce its funds to AIDS was thwarted, and flat funding has been renewed.
- The Subcommittee suggests developing a Recommendation for the December meeting on the Federal Government's continuing to fund UNAIDS.
- A good relationship has developed between the International Subcommittee and NORA, which is monitoring issues that PACHA follows.

**International Recommendation:** Dr. Weniger, noting that this is a propitious time for a Recommendation for support of UNAIDS with the budgetary process in progress, drafted a statement, which was approved by the Council, as follows:

The Presidential Advisory Council on HIV/AIDS requests Ms. Sandra Thurman, Director of the White House Office of National AIDS Policy, to convey the Council's strong support for the unique role of UNAIDS for leadership, technical assistance, and advocacy for developing countries in the global effort to control the HIV/AIDS pandemic, and the Council's desire to see continued strong financial support for UNAIDS by the U.S. Government.

### **Letter to the President**

The Council agreed to send an interim letter to the President regarding the perception that the national AIDS program is not as strong as it has been in the immediate past, progress to date on PACHA Recommendations, and notice that a full evaluation will be made in the Council's 1997 Progress Report in December. Mr. Isbell, Mr. Henderson, and Rabbi Edelheit drafted the letter, based on input from Committee Chairs, and during the PACHA meeting several revisions were made by the full Council. The final letter (attached at the end of this report) was approved unanimously and will be sent to President Clinton through ONAP as soon as possible.

### **1997 Progress Report**

The Council addressed the problem of determining an overview of the tone, content, timing, and prioritization of issues for its 1997 Progress Report, which will be drafted by the Process

Committee over the next few weeks, finalized during the winter meeting, and delivered to the White House in December. Its goals are to assess responses to date from the Administration to all PACHA Recommendations, identify which Recommendations have not been addressed, and prioritize unrealized Recommendations as appropriate.

Several members believed that PACHA needs to cut down on the number of issues to be brought before the Administration in order to strengthen its main goals, and Dr. Cade suggested that each Committee focus on one particular issue. Mr. Anderson agreed that priorities are needed, but that the epidemic is too complex to disregard other actions. It was noted that institutionalization of small issues may have the greatest impact; and it generally was agreed that issues should be institutionalized as much as possible and said that there is a need to focus now on who is responsible for issues and to develop global strategies.

It was urged that the report not be just a report card, but a 2-year report as well, representing PACHA's thinking behind the Recommendations. Others cautioned that it should be to the point and interesting, saying that the Recommendations often appear to be boring: the cover should elicit a response; the text should focus on specific things that must and can be done; and the report itself should be brief and bulleted, with an appendix containing background and rationale. It was agreed that the document would include an executive summary, brief report, and appendix.

Mr. Fogel believes that the Council spends too much time on format and now should consider specifics, directing its attention toward the easiest issues to accomplish—needle exchange and discriminatory practices in agencies. Mr. Sasser suggested that the Council might garner more visibility with a State-of-the-Epidemic report, along with the assessment, and a number of members agreed.

### **Turning Up the Heat**

The primary concerns of the Council are that it has been too passive in the past in pursuing its own goals and that it needs to be assertive with the White House, but that it has not identified exactly what will influence the Administration. The threat of being thrown off the Council may keep members silent on such thorny issues as Secretary Shalala's and DHHS' effectiveness in AIDS-related actions.

Most members agree that PACHA needs better visibility for its work and Recommendations; that it needs to learn how to use the press better and must use its political contacts and abilities to gain access to influential people to make things happen. Dr. Weniger said, "We must find a way to convince the press that our Recommendations are newsworthy."

That PACHA needs to collaborate with other entities in the AIDS community is a given. Mr. Sasser urged PACHA to develop a legacy of strategizing with the community to obtain its support and to gain better visibility. As an outside observer, he said, he had no idea that the Council was behind the White House Conference on AIDS, and he said that activities like World AIDS Day and a yearly State of the Epidemic could help.

The consensus is that a plan must be developed immediately and action aggressively taken. Although our “official role is to advise,” Mr. Hattoy said, “we have to make things work.” That the White House has a “well-oiled staff who knows what we want and what is going on is a myth,” he said, saying that PACHA should use phones, faxes, e-mail, city mayors—creative things to put the pressure on the Administration. Ms. Miramontes noted that in this epidemic no one has ever gotten much done solely in an advisory capacity.

Mr. Johnson agreed that people should be held accountable, particularly if it is an issue in which the President has declared it to be “a go.” Dr. Gutierrez suggested that the Council remove the confusion from what it needs to do: “If Secretary Shalala refuses to meet with us, we should tell the Administration she is being an obstacle.” Mr. Bollman said that the Council could call for Secretary Shalala’s resignation, if necessary.

Mr. Sasser asked if the Council was afraid of being independent and aggressive, saying that his perception is that PACHA is not doing enough. To be effective, it has to publicly recognize Administrative failures as well as successes. Ms. Thurman agreed that urgent action is needed. Dr. Hitt said he recognized the need for action and is willing to empower the Process Committee to act quickly, while keeping members informed.

Mr. Fogel advised caution and use of ONAP to put pressure on the President, and Mr. Henderson said that the Council should not get into micromanagement. The President has a personal commitment on this issue, he said, and the Council must accept him at his word; however, where others are standing in the way of that commitment, it has to be brought to the President’s attention. Dr. Hitt agreed that PACHA should try to work through Ms. Thurman and her office as much as possible and that she should be involved in all Process Committee conference calls.

### **Motion for Council To Resign**

In order to stress the urgency of the need for Administrative response, Mr. Fogel suggested that an ultimatum be given to the Administration with a December deadline for taking action on Council Recommendations. “I am willing to stake my stay on the Council on their meeting this deadline,” he said, and urged other PACHA members to do the same. He moved that the Council resign *en masse* if proper Administration response had not been given by December. The motion was seconded, and Mr. Stafford said he would not continue to participate if the White House does not act on its promises. Mr. Robinson said that this will put the issues clearly on the table, sending a message of protest to the President, and agreed that it is advisable to leave the Council if the Administration does not do something—at least on needle exchange.

Other members, however, asked the Council to use reasonable means to reach its objectives. Mr. Henderson noted that the interim letter to the President clearly put the Administration on notice that its responses will be publicly assessed in December.

Dr. Gutierrez noted that personal resignations do not create news, that no one will care, and that someone else will fill the vacancy.

Mr. Johnson suggested that the motion be withdrawn, so as not to send confusing issues to the Administration, saying that Ms. Thurman can convey the message of PACHA's frustration to the Administration. The motion was withdrawn, with the provision that this issue be included in the December meeting agenda.

### **Four-Month Action Plan (Through December Meeting)**

The goal should be to have as much response from the Administration as possible before the Progress Report is finalized to develop a win-win situation, Dr. Hitt said. PACHA must be more proactive in getting Recommendations completed and develop an ongoing process and ability to engage at strategic points. The Council's effectiveness is being lowered, said Mr. Isbell, because we focus on these meetings and not much in between, and members need to commit to doing specific tasks, such as setting up meetings with Gen. McCaffrey and Secretary Shalala.

Suggested actions included:

- Meet with key players in the community, such as Dr. Paul and Dr. Baltimore, to get input, recommendations, and assessment of the President's work.
- Coordinate efforts with other AIDS organizations, and develop specific mechanisms for doing so.
- Develop strategies with allies such as NASTAD, the National Governors' Association (NGA), and AIDS Action Council.
- Include NORA. It covers all organizations under discussion, and ONAP is already working with this group. Consider setting up a meeting with them.
- Determine what the Council wants its legacy to be, and pursue that.
- Use members' network of friends and contacts.
- Turn up the heat on the Administration, HUD, DHHS, and others.
- Piggyback meetings with Government entities when members are in Washington for other groups; use resources in the Capital.
- Have press followup and meetings with community-based organizations to give PACHA and ONAP efforts better visibility and to maintain public interest in AIDS.
- Set up meetings with people on such issues as return-to-work.

To develop the Process Plan and Action Plan drafts, Dr. Hitt suggested these steps:

1. Each Committee should submit its priorities and action plan, along with the one thing that would move its issues forward the most, by early next week.

2. Using Mr. Montoya as a focal point, members should coordinate visits to Washington and look for new resources for getting to the Capital for additional, in-person meetings.
3. Leadership will communicate with NORA and NGA to see how to synergize and not overlap. Ms. Thurman was asked to let PACHA know the best organizational resources.
4. The Process Committee will meet via conference calls following this meeting to develop the master action plan over the next 2 to 3 weeks, and a draft will be submitted to the full Council for review and revision.

Mr. Robinson suggested that the Council be given the revised Progress Report at least 4 to 5 weeks before the meeting so that it can be close to final stages in December and so that a proper rollout campaign can be developed.

### **New Business**

**New Faces, New Views:** Dr. Hitt introduced ONAP's Deputy Director, Mr. Summers (from the Housing Department in Boston), and welcomed him to ONAP and PACHA. New Council members were asked to give their backgrounds to the rest of the group, and Dr. Gutierrez said she was impressed with PACHA and the openness of its members. A primary care internist in practice since 1980, her clinical and organizational experience has been in New York City, beginning with training and work at Harlem Hospital. She has been Director of AIDS for the City, creating guidelines for treatment and organizing the largest AIDS program in the country with an excellent continuum of care. Of special concern are marginalized people, women with AIDS, and people of color.

Mr. Sasser, who has been HIV-positive for 10 years, has extensive background in working with young people, education, advocacy, and training leadership. He has been on many boards, councils, and working groups for AIDS, has worked in San Francisco, and now is in Atlanta, pursuing his passion for fighting the disease.

**International Vaccine Initiative:** To facilitate collaborative work, Ms. Miramontes moved to add PACHA's name to the IAVI list of organizations calling for international vaccine development. Mr. Henderson seconded the motion and, after some discussion, the motion was passed unanimously.

**Address Changes and Scheduling:** Dr. Hitt asked members to give any address changes and scheduling information to Mr. Montoya. Members should turn in 1998 meeting preference dates, and Committees should submit conference call schedules within the next 2 weeks; all calls should be scheduled at least 30 days in advance.

**Next Council Meetings:** The next full-Council meeting will be held December 4–7, 1997, at the Omni Shoreham Hotel in Washington, D.C. It was determined that 3 full days are needed for the winter meeting, and the final day's session is scheduled to end at 4 or 5 p.m. The meeting will include two panel discussions—on the whole issue of substance abuse, including needle exchange,

set up by Mr. Anderson and Mr. Landau, and racism, with Ms. Fraser-Howze as lead. Dr. Hitt said that, by October, the Council should have names of participating panel members and background materials.

On conference calls, the Process Committee, plus others who work on the assessment (Ms. Miramontes, Mr. Henderson, and Dr. Cade) will meet at 10 a.m. Eastern Time on Wednesdays; the Research Committee will meet at 10 a.m. Fridays, beginning August 15.

### **Closing**

Ms. Thurman thanked the Mayor and Police Department of Atlanta for providing security for the meeting, and the Council thanked her and AID Atlanta for hosting a PACHA reception at the ONAP Director's home. Dr. Hitt thanked Council Members, ONAP staff, and guests for their participation, and the seventh meeting of PACHA was adjourned at 2:00 p.m., July 25, 1997. Committees continued to meet thereafter and to develop written Action Plans, which have been included in these Minutes.