Presidential Advisory Council on HIV/AIDS

December 15-17, 1996

Hyatt Regency Washington
Washington, DC

MINUTES

Present: R. Scott Hitt, M.D., Chair; Stephen N. Abel, D.D.S.; Terje Anderson; Judith Billings; Mary Boland; Nicholas Bollman; Tonio Burgos; Jerry Cade, M.D.; Rabbi Joseph A. Edelheit; Robert Fogel; Debra Fraser-Howze; Kathleen Gerus; Phyllis Greenberger; Robert Hattoy; B. Thomas Henderson; Michael Isbell; Ronald Johnson; Jeremy Landau; Alexandra Mary Levine, M.D.; Steve Lew; Helen H. Miramontes; Altagracia Perez; Robert Michael Rankin, M.D.; H. Alexander Robinson; Debbie Runions; Benjamin Schatz; Richard W. Stafford; Denise Stokes; Sandra Thurman; and Bruce Weniger, M.D. Also present from the Office of National AIDS Policy (ONAP): Patricia Fleming, Director; Sherry Darden, Patricia Milon, Daniel Montoya, LaHoma Romocki, Jane Sanville, Richard Sorian, and Adam Sutton.

Absent: Regina Aragon, Carole laFavor, and Charles Quincy Troupe.

Opening and Interim Business

Dr. Hitt, Chair, dedicated this fifth meeting of the Presidential Advisory Council on HIV/AIDS (PACHA) to the memory of Ed Gould for his dedication to HIV-related youth, civic, and educational issues. He thanked Mr. Bollman for taking on Services Committee leadership and welcomed new member Rabbi Edelheit. Dr. Hitt summarized interim Council activities:

PACHA rechartering and staffing: After meeting with the Deputy Secretary of the Department of Health and Human Services (DHHS), Dr. Hitt and Mr. Henderson reported that "chances are good" that DHHS will recommend PACHA rechartering and staffing, through ONAP, with Mr. Montoya coordinating Council activities. Although PACHA is chartered for only two meetings per year, plus a limited number of conference calls, funding is being sought for a third meeting and additional calls, particularly for working committees. During the meeting with DHHS, PACHA also gave its recommendations for future ONAP leadership and activities.

4-Year Goals: PACHA's Four-Year Plan was amended to include two new long-term outcome goals, as follows:

- Accelerate the development of new and more effective HIV treatments to enable people with HIV to live normal and fully productive lives.

- Increase the U.S. commitment and support for international efforts to address the global AIDS epidemic.

HIV/AIDS Federal Support Survey: Dr. Hitt and Ms. Billings presented a revised questionnaire, which was modified to include new outcome goals and approved for distribution to White House Conference participants, AIDS service organizations with AIDS policy departments, smaller related agencies (list to be compiled by Mr. Anderson), and others who Council members feel should be included. It was suggested that the survey also be sent out on the Internet, through the National AIDS Clearinghouse, and that large organizations be asked to forward copies to others who might have input. The mailing will include PACHA's Executive Summary and information on how to obtain its full report. Replies will be directed via mail only to Mr. Montoya, and a summary of findings will be sent to questionnaire respondents. Dr. Hitt thanked Mr. Henderson and Ms. Billings for their help in developing the survey.

Council Communications and Public Relations: The Council needs better communication with the AIDS community for external input and for a stronger public relations program. More effort will be put into receiving media coverage, if staff is made available to PACHA for this purpose. In the meantime, the Process Committee will discuss ways of facilitating communications, and media coverage will be coordinated through ONAP by Mr. Sorian.

ONAP Update

Ms. Fleming, outgoing Director, reviewed 1996 ONAP accomplishments, including the President's Proclamation on World AIDS Day, reauthorization of the Ryan White CARE Act, release of the first National Strategy on AIDS, a "blueprint for action in the year ahead," and Regional Community Briefings. The Administration's ongoing commitment is reflected in the following 1997 budget increases to AIDS programs: Ryan White, 31.5 percent; AIDS Drug Assistance Program (ADAP), 221 percent; Housing Opportunities for People With AIDS (HOPWA), 14.6 percent; and the CDC AIDS prevention programs, 6 percent. NIH AIDS research funding has increased 6.7 percent, and authority has been restored to the Office of AIDS Research (OAR) to determine allocation of funds. This increased base should be protected in 1998, and the Administration will continue its defense of Medicaid, although the program is "still vulnerable."

Results from combination therapies are encouraging, and the Administration is trying to answer questions on efficacy through outcome trials and other methods. The NIH has held the first of a series of meetings with AIDS researchers to determine what information is needed, and an advisory panel of outside experts has been established to study how results and treatment programs can best be conveyed to the health care community. Ms. Fleming thanked the Council for its support of ONAP programs and members of her staff, including outgoing Deputy Director Jeff Levi, for their commitment to both ONAP and PACHA. She assured the Council that continuity will be maintained when new directors are appointed. The Council thanked Ms. Fleming and Mr. Levi, who both will continue working on HIV/AIDS issues.

National Strategy on AIDS

The final version of the National Strategy on AIDS was presented by Ms. Sanville, who said that most suggestions made by PACHA and other AIDS organizations had been incorporated. She reemphasized that this is a baseline for future, more inclusive strategies and implementation

planning. Dr. Hitt proposed a Council resolution commending the National Strategy on AIDS, but members expressed concerns centering around critical issues and PACHA recommendations that are not addressed thoroughly. The consensus is that the Council does not want to endorse the National Strategy as it stands; however, the document provides a foundation on which to build, and it is important for PACHA to acknowledge this first step by the Administration to develop a global plan of attack on the epidemic. The resolution incorporated was approved as follows:

> The Council commends the President and the Office of National AIDS Policy for demonstrating leadership in developing the Federal Government's first national comprehensive strategy for dealing with the HIV/AIDS epidemic. While there are clearly significant issues regarding the epidemic which still must be addressed, the National Strategy on AIDS provides a foundation for the Federal Government's response to HIV/AIDS in the year ahead. Specific implementation tactics and strategies must be developed.
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> The Council believes that, in order to have any realistic chance of achieving the President's stated goals of finding a cure, developing a vaccine, and reducing annual new infections to zero, other important issues, such as how to decrease infections among intravenous drug users, must be addressed more comprehensively.
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> The Council intends to continue to ensure that all crucial issues are dealt with and that the actions of relevant Federal agencies are consistent with the National Strategy on AIDS and with PACHA recommendations.

Vaccine Update

At the request of Dr. Levine, Research Committee Chair, the latest developments in vaccine research were presented to the Council by Dr. Bonnie Mathieson, Chair of the Vaccine Coordinating Committee at OAR. Highlights included:

- Special funds were set aside for the National Institute of Allergy and Infectious Diseases' (NIAID) new vaccine initiative group headed by Dr. David Baltimore, who is forming task committees and surveying regional virologists and immunologists. Outside experts and intramural activities will be integrated into this trans-NIH effort.
- An additional $6 million has been allocated for research on preventions other than vaccines, e.g., behavioral issues and microbicides.
- A prevention working group was established with the CDC to consider these issues.
- Several recommendations from the Levine Evaluation Task Force Report have been initiated, including institution of a program equivalent to the Public Health Services (PHS) vaccine cross-agency cooperation.
- The OAR is committed to a broad program on vaccine research, including clinical trials at various phases both in the United States and abroad.
- Dr. Mathieson is PACHA's point person within OAR; Carole Hielman, Ph.D., Deputy Director of the Division of AIDS, is the contact at NIAID.

- A developing concern is that the public, considering the epidemic to be ending because of new therapies, may lose interest in vaccine development. The AIDS community needs to offset this misconception and continue to promote vaccine research.

CDC HIV/AIDS Update

During a Prevention Committee meeting open to the full Council, Mr. Anderson, Acting Chair, introduced Dr. Helene Gayle, Director of the National Center for HIV, STD, and TB Prevention of the CDC, and Gary West, Deputy Director, who gave an overview of relevant CDC programs. The major points were as follows:

- The CDC has reassessed and reorganized its research activities, directing 80 percent into the new Center headed by Dr. Gayle.
- Prevention is approached as "an intersection of science, programs, and policy," and the CDC's mission is to provide the science basis for preventing and controlling the disease, focusing on such increasingly high-risk populations as injection drug users (IDUs), women, youth, young gay people of color, and prisoners/parolees.
- Current and future goals include gaining better understanding of transmission factors and natural history; developing new and enhanced behavioral interventions; evaluating new testing opportunities, the use of STD treatments in prevention, and the impact of the process and outcomes of programs; and monitoring HIV variants and resistance in epidemiological and biomedical interventions. Other issues are early HIV detection, prenatal monitoring, enhanced security of HIV/AIDS data, behavioral surveillance, client center counseling, access to testing and counseling, and education of health care professionals and legislators.
- Challenges center around accountability of programs, evolving Federal roles in prevention, evolving health care delivery systems, integration with STD treatment and other public health issues, and the politics of prevention.
- The CDC helps community programs through technical and financial assistance, dissemination of information, training, and monitoring national trends. These programs are held accountable through withholding of funds or restricting budgets. Both funding and representation of HIV/AIDS issues are uneven, obtaining funds for local AIDS programs is difficult, and the CDC does not have financial and human resources needed to set up optimal programs; however, all are "doable."
- In answer to Council requests to the CDC for statistics, budgets, and seroincidence estimates to help develop prevention programs among specific populations, some numbers are immediately available, but it is unlikely that accurate seroincidence figures in specific populations can be obtained soon.
- Guidelines for HIV-infected health care workers are being developed.
- CDC partnerships are being set up with other Government agencies, as well as local organizations, to prevent overlaps in such areas as behavioral research.
- The CDC is trying to make prevention education material contents as unrestrictive as possible; however, there are still overwhelming political implications and objections from parents on prevention education in schools. (Ms. Runions pointed out that her organization—DASH—has made significant inroads through meetings with objecting parents; bringing the opposition into the planning process helps to convert them.)

- Critical vacancies in CDC leadership should be filled by the end of January.
- Although the CDC believes that needle exchange reduces infections, it still seeks proof that drug use is not increased, and any statement will have to come from Secretary Shalala. (Dr. Levine noted that the proof is available and that "this is the moment of opportunity" for being a leader in the needle-exchange movement.)

After stating that PACHA can play a key role in CDC programs, Dr. Gayle invited the Prevention Committee to visit CDC in Atlanta and noted that Ms. Billings is representing PACHA on a new agency committee on HIV and STDs.

Prison Issues

The current status of the issue of prisoners and HIV/AIDS in the United States was described by a panel of experts convened by the Prison Committee to provide background on related issues for the Council. Mr. Landau, Committee Chair, dedicated the presentation to the memory of Dr. German Maisonet, a leader in prison reform. Ms. Gerus introduced the speakers.

Dr. Kenneth Moritsugu, Medical Director, Federal Bureau of Prisons, and Assistant Surgeon General of the United States, said that the prison population, which includes some 107,000 inmates infected with HIV, is shifting toward more drug-related crimes, more female prisoners, and longer incarcerations. Pointing out that the Bureau has no jurisdiction over State, county, or local prison systems, he described Federal HIV policies and programs as "humane to prisoners," with a mission to provide a balanced system of care and custody benchmarked by community standards, CDC guidelines, and universal precautions. Components include professional care and treatment with AZT, protease inhibitors, and other FDA-approved medications; continuing education for inmates and prison staff; hospice programs; drug abuse treatment; female health care; participation in joint programs with communities; and compassionate release.

HIV-infected prisoners are not segregated from the general prison population, he said, and when feasible, hospitalization is in outside community facilities or a specialized prison medical referral center. Inmates are allowed to enter voluntary drug trials studies and other area programs. Testing is random among 10 percent of the population upon entry and when monitoring seroconversion or when clinical signs of infection exist or an inmate volunteers for testing. The Bureau has had a "zero transmission rate" over the past 10 years. Dr. Moritsugu asked the Council to provide ongoing input to help improve the national system.

Dr. Linda Frank, Director, Pennsylvania AIDS ETC, Assistant Professor in the University of Pittsburgh School of Public Health, and Chair of the Prison Health Committee of the American Public Health Association, said that there are many critical health problems within corrections facilities, including substance abuse, HIV infection, tuberculosis (TB), and STDs. Challenges include overcrowding, overburdened medical staff and resources, conflicts between control and security and patient care, lack of understanding of inmate and provider needs, and lack of cultural sensitivity and linguistically appropriate services. Inmate issues include coping with disease, isolation, loneliness, and fear of dying in prison; lack of privacy and confidentiality; and poor access to care and clinical trials. The greatest opportunities for HIV prevention are during initial assessment and placement, transfers to new programs, ongoing primary care, and prior to and

after release. Successful programs within the Pennsylvania State prison system depend on adequate training of corrections administration, medical and counseling personnel, probation and parole personnel, and inmates who provide peer-based counseling. The latter is critical in prevention and treatment, as it gives inmates increased self-esteem, self-efficacy, and new skills as well as offering a safe network for prisoners who need counseling and care.

Mr. Willy James Byrd, Group Facilitator, Community Outreach Programs, Ex-Offender HIV Coalition, said that the reality of being HIV-positive in prison is "very bad." Many problems and inconsistencies exist: Prisoners are reluctant to voice their needs or suspicions of infection because of discrimination by other inmates and officials; correctional staff generally are uncaring and unknowledgeable; confidentiality does not exist; inmates do not have adequate education, information, medications, care facilities, or followup mechanisms such as release counseling and financial assistance; and current compassionate release criteria are not realistic. Peer education and prison community outreach are urged; having "someone who cares" is the key to zero transmission.

Ms. Madeline Burt, HIV Community Coalition and Network Reachout Programs, ex-offender and recovering addict, said that in the Washington, DC, prison system, she did not receive pre- or post-testing, counseling, or education, and medical personnel were not familiar with associated female health issues. Medical corrections personnel and inmates treat HIV-infected prisoners "like animals," and many patients die from lack of medication and proper care, often alone and ostracized. Others, when released, are given no medication, insurance, or counseling and are often sent to halfway houses without proper care facilities.

Ms. Jackie Walker, AIDS Information Coordinator, American Civil Liberties Union (ACLU) National Prison Project, spoke of gaps in policies and treatments; staff and peer education; and practical preventive systems; she said high-risk sex and drug abuse are rampant. She cited ethnic culture and language problems, especially among Latinos and African Americans, and special issues of female inmates. Continuity is needed in both mental and physical health programs, from initial testing to release. Adequate information must be made available to prisoners, along with access to clinical trials, discharge planning, and transitional health care. For models, she recommended the Canadian national program and two current, successful peer education programs within the Federal Bureau of Prisons started by political prisoners.

Mr. Tommy Reeder-Bey, National Association of People With AIDS (NAPWA), and **Eric Turner,** HCC, ex-offenders working with community-based organizations, reinforced the need for change in the overall system. Recommendations include better education and care, more humane treatment for the ill, cooperation with inmate outreach and peer education systems, and adequate release programs that include information about Medicaid and other financial assistance because inmates who receive no help after release often repeat offenses. To be effective, recommendations and programs must involve inmates and community-based organizations.

Council members questioned Dr. Moritsugu about Federal statistics, particularly "zero transmission," and the view of ex-offenders that prison prevention programs are ineffective. PACHA Members and public spectators commented on the apparent lack of full care for prisoners with HIV as described by former inmates, including two individuals from the federal system who

found it to be as ineffective as the others. Dr. Moritsugu acknowledged that there are weaknesses in the system and that the zero conversion rate is based on the 10 percent random sampling. Current prevention programs do not utilize condoms, bleach kits, or needle exchange.

Recommendations to PACHA focused on continuing education, peer educators, access to testing and counseling, confidentiality, integration of people with HIV and TB into the general populations in institutions, access to quality care and clinical trials, compassionate release, and discharge planning that links parolees with what is available in the community. PACHA and prison systems must include input from infected inmates in developing HIV policies and appoint current and ex-prisoners to groups such as PACHA and its committees. Mr. Landau indicated specific recommendations will be made to the President in the near future. He thanked the speakers, public attendees, and NORA for its help in developing information on prison issues.

Welfare Reform

Dr. Hitt introduced **Mr. Jeremy BenAmi,** outgoing Deputy Assistant to the President for Domestic Policy and Welfare Reform, thanking him for his work with PACHA, the National AIDS Strategy, and current welfare reform efforts. Mr. BenAmi described several areas of current interest on welfare reform within the Administration:

- Implementation efforts include an interagency working group, made up of the directors of various mid-level organizations, which meets weekly to try to minimize the effects of new welfare legislation.
- The current legislative arena regarding amendment is critical, especially in the Administration's efforts to restore funds in areas where cuts were made, such as food stamps, housing subsidies (excess shelter program), and indexing. PACHA urgently needs to muster legal arguments for these amendments and to offer advice to the White House.
- More than $3 billion in tax credits and subsidies to employers to aid the process of moving people from welfare into work has been suggested by the President, with goals of moving 1 million people over the next 3 years and providing subsidies for local community welfare programs. Incentives to employers to provide adequate health coverage for employees not eligible for Supplemental Security Income (SSI) are not needed since the link between welfare and Medicaid has been severed; however, they may be needed for higher-wage, higher-skill jobs. Medicaid is being pushed toward extension of State waivers, and providing health coverage for 2 or 3 years after leaving welfare is an important bridge in welfare-to-work.
- Welfare reform for children orphaned by AIDS is focused on foster care, currently funded under Section 4E, and some States are experimenting with subsidized guardianships.
- A report on teen pregnancy will be issued in January, and there is a "realistic chance" that prevention programs not based on abstinence will be developed by the Government, with emphasis on local-level involvement.
- Key White House welfare contacts during transition are Diana Fortuna, implementation; Lynn Hogan, welfare-to-work and children; and Chris Jennings, Medicaid.

A letter on welfare system issues written by Mr. Isbell has been sent to the President. and it was hoped that a reply is forthcoming.

Access to Treatment Presentation

A panel on access-to-treatment issues was convened by the Services Committee, and Mr. Bollman, Chair, introduced the speakers.

Ms. Susan Daniels, Return-to-Work Issues, Social Security Administration (SSA), highlighted work incentive provisions and safeguards under disability insurance (DI) and SSI, saying that people on welfare are more concerned about losing access to health care than income. In fact, most do have access to health care, but the system is so complicated they do not believe they can access it. Weaknesses include differences in State requirements, wage thresholds disproportionate with price of health care, and the "all-or-nothing" nature of cash benefits for DI beneficiaries which makes work financially unattractive. Ability to work fluctuates with most chronically disabled people. Congress, therefore, needs to redefine "disability," and SSA programs should be more flexible to allow these people to go in and out of the system, as needed. Dr. Daniels advised PACHA to ally itself with organizations with similar problems, such as those serving people with other disabilities.

Dr. Richard Moore, Cost Benefit/Data Analysis, Johns Hopkins University, described a study of the cost effectiveness of administering medical interventions based on new HIV/AIDS antiretroviral therapy. It was found that the annual cost of administering a typical triple-drug combination is about $11,000 per patient (average wholesale price) and life expectancy is extended by at least 3 years. Although monotherapy costs much less, the cost per year of maintaining a very ill person rises exponentially with associated complications of AIDS and the inability to work. Costs of multiple therapy are offset over a few years as quality of life improves. Coincidentally, the annual costs of medications for people with other critical diseases, such as coronary heart problems and cancer, are much higher than that of antiretroviral therapy.

Dr. Eric Goosby, Director of Office of the HIV/AIDS Policy, DHHS, described the development of a new standard of care based on multitherapy treatments. Seeing a marked drop in viral loads of patients on a combination of AZT, 3TC, and protease inhibitor (Indinavir)—90 percent or better, versus 50 to 60 percent for those on AZT alone and 70 to 80 percent for those on a nucleoside/AZT combination—DHHS recognized that this information had to be synthesized and disseminated rapidly. With the OAR, DHHS is developing a database wherein standards and guidelines of treatment gathered from panels of leading clinical experts will be distributed through the Public Health Service (PHS) via the Internet and mailings and updated continually. The system will be accessible to related agencies to facilitate incorporation of new treatments into funding programs, medical health care personnel and patients seeking the most up-to-date recommendations, and third-party payers. DHHS hopes to publish the first set of guidelines by February and to add other factors such as opportunistic infections (OIs) as soon as possible. It also is hoped that these guidelines will be a leverage for States and municipalities when exploring cost considerations and best-decision paths for funding treatments and to show third-party payers that combination therapies are the most cost effective. International guidelines are planned, with help from the World Health Organization (WHO).

Ms. Christine Lubinski, Deputy Executive Director, AIDS Action Council (AAC), addressed Medicaid-Medicare issues. She urged the Council to protect the existing system and to be proactive about recommending enhancement of the program. Currently, more than half of adults and 90 percent of children with HIV/AIDS depend on Medicare, and this number will increase. As HIV/AIDS patients live longer, Medicare coverage is increasingly important, but it has inadequacies and is vulnerable to deficit budgetary attack. Getting Medicaid help is problematic because most people must be totally disabled to gain access to the program. The Administration will likely unveil a per capita cap for Medicaid, which will have grave implications for persons living with HIV/AIDS (PLWHA) because it establishes a Federal limit on the amount of money allocated to each State for Medicaid beneficiaries (primarily women and youth, seniors with long-term care needs, and people with disabilities). Budget cuts should not undermine vital services to individuals with low income and complex health care needs; prescription drugs should be a mandatory benefit; enhanced capitation is needed for complex and costly medical conditions, particularly in States with the highest HIV/AIDS populations; and consumer protection must be provided in managed care, especially if the Federal waiver process is eliminated, since these organizations will be the primary source of PLWHA care under Medicaid and, possibly, Medicare. Other recommendations include job training for people with disabilities, education of ourselves and our constituents about Medicare benefits, programs for people living in poverty, and access to supplementary coverage for Medicare beneficiaries at realistic prices.

Dr. Joe O'Neill, Ryan White Issues, Health Resources and Services Administration (HRSA), described the HIV/AIDS care system as "complex and overwhelming." Focal issues affecting Ryan White include the following: (1) proper medical care for PLWHA, especially new treatments; (2) a growing distrust of the Government's ability to do anything well, which mandates a more critical study of program outcomes; (3) the impact of managed care and the need to find ways for it to cover PLWHA; (4) increasing penetration of HIV in new populations; and (5) budget concerns, particularly in the current troubled financial environment. HRSA needs to determine how to balance accountability with provisions for people needing food, shelter, and medical care. He asked the Council to consider these issues and to provide HRSA with feedback concerning its performance.

In answer to Council questions, Dr. O'Neill said that HRSA can quantify how much of the Ryan White program funding is spent nationwide on medical services versus supportive or enabling services only within Title III, wherein 50 percent or more must be spent on primary care. With diversities existing among communities, an advantage of the Ryan White program is local control. In evaluating Ryan White, HRSA has identified gaps, starting with consumer satisfaction, but the agency has not yet devised methods to quantify its effects.

Mr. Bollman thanked the speakers and Mr. Anderson and Mr. Lew for their help in developing recommendations to be presented to the Council. In summary, needs include maintaining current programs while thinking about new ones, having social research with sufficient numbers to support recommendations; implementing highest-level policy dialogues among States; testing new ideas and finding concrete outcomes; developing allies; and building coalitions across constituencies to make sure new systems serve everyone.

Committee Meetings and Reports

Following are summaries of committee activities and reports given to the Council during the PACHA meeting.

Prison Issues Committee

The Prison Issues Committee met on December 15 to finalize recommendations made during several conference calls and future plans, with Dr. Abel, Dr. Cade, Ms. Gerus, Mr. Landau, and Ms. Milon present. Later, Mr. Landau and Ms. Gerus convened a panel discussion for the full Council on prison issues (see above). In a report to the Council, Mr. Landau addressed member questions, including clarification of PACHA's limitations and ability to have an impact on the overall prison system and what recommendations can be made to the Administration. This type of information is coming from such groups as NORA, and the committee will prepare a statement about the Council's jurisdiction at the April meeting. Other issues involve the need to identify all Federal funding streams for State and local prisons, clarification of prisoner benefits following release, and jurisdiction issues concerning the Washington, DC, prison system.

Mr. Landau said that prison AIDS incidence is much higher, the lack of services more serious, and the percentage of vulnerable populations, especially African Americans, is much greater than that of the general public. The Prison Issues Committee presented a request for a comprehensive report from the Bureau of Prisons and the Department of Defense addressing HIV/AIDS issues in all federal and military prisons and brigs. The request was approved, with changes, as was a Prison Issues recommendation (see New Recommendations section below).

The committee presented a time line for future activities that included increased interaction with the Prevention Science Working Group, monitoring related discrimination and international issues, reviewing current resources on AIDS and prison issues, asking ONAP to convene a national forum on prison issues, and developing followup recommendations.

International Issues Committee

The International Issues Committee met December 15 to develop amendments for Council recommendations and an addition to the PACHA 4-year outcome goals (see above). Mr. Fogel acted as point person, with Mr. Bollman, Mr. Lew, Ms. Cynthia Marial of the NCIH, Ms. Miramontes, Ms. Romocki, Ms. Runions, and Dr. Weniger also present. Mr. Fogel reported that the Administrator of USAID, Brian Atwood, acknowledged Council concerns about USAID staff vacancies and the need for information and skills exchange between domestic and foreign AIDS groups on care, treatment, and the protection of human rights. Partially as a result of PACHA's recommendations, USAID has convened a meeting among nongovernmental organizations (NGOs) and filled most of the critical vacancies. The committee will continue to gather information about the Department of State's 1995 International Strategy on HIV/AIDS, the status of AIDS as a national security issue, and the USAID's HIV/AIDS Division, and review the International Provisions of the National Strategy on AIDS. Mr. Fogel will represent the Council at an international conference to encourage more global sharing and better press coverage of HIV/AIDS issues, in the Ivory Coast in February.

Discrimination Committee

The Discrimination Committee met on December 15, with Mr. Schatz acting as point person; Mr. Hattoy, Mr. Johnson, and Mr. Montoya were also present. In a report to the Council, Mr. Schatz said that a committee survey on discrimination issues indicated areas for future study:

- The current law that sets up potential testing of newborns, its leeway, and enforcement, in conjunction with the Administration and Mr. Sorian.
- Potential new legislation regarding mandatory testing, contact testing, and reporting, in conjunction with the Prevention Committee.

The committee is focusing on how well past recommendations have been addressed and will apply pressure on the Administration to address unanswered issues such as HIV testing in the foreign service, Peace Corps, and military. The committee will try to meet with each of the groups involved, with help from ONAP. In reviewing the National Strategy on AIDS, the Discrimination Committee expressed its disappointment in the number of agencies that failed to respond on issues of civil rights and requested that ONAP recontact certain of these agencies, such as DHHS, for Appendix additions.

Suggestions for future Discrimination Committee recommendations involving racial and military discrimination were made by members, but Mr. Schatz pointed out that most of these issues would be covered in other committees. For committee background on racial discrimination, Ms. Fraser-Howze will obtain a 1994 Johns Hopkins report that provides pertinent statistics. A proposed Discrimination Committee recommendation on medical use of marijuana was tabled.

Prevention Committee

The Prevention Committee met on December 15 and jointly with the Research Committee on December 16, with Dr. Abel, Mr. Anderson, Ms. Billings, Ms. Fleming, Mr. Fogel, Ms. Gerus, Dr. Hitt, Mr. Isbell, Mr. Johnson, Mr. Landau, Mr. Lew, Ms. Perez, Ms. Runions, Mr. Schatz, and Ms. Stokes present. In Mr. Robinson's absence, Mr. Anderson reviewed input from Dr. Gayle (see above). In trying to define the CDC's $6 million funding for HIV prevention, the Prevention Committee hopes to visit CDC before the next PACHA meeting. A short presentation at the next meeting was requested so that CDC could provide specific global epidemic numbers and underlying issues to the Council.

Prevention is seen as a "step-sister," and the committee hopes to bring it to a more equitable position in the overall national agenda. Future activities include development of a panel on prevention for injection drug users (IDUs) and realities of needle exchange; meeting with various community organizations to ascertain their needs; making HIV education in schools a priority; working with the Research Committee to include social and behavioral sciences in the national agenda; developing recommendations on the Federal role in testing and counseling; monitoring biological and social implications of new treatments, biological prevention, and social impact; and focusing attention on issues that have not been adequately addressed, such as prevention for women of color and Latinos.

Services Committee

The Services Committee met on December 15 and 16, with Mr. Bollman, Chair, and Dr. Abel, Mr. Burgos, Ms. Fleming, Mr. Henderson, Dr. Hitt, Mr. Lew, Dr. Rankin, and Barney Singer of SPNS also present. Mr. Bollman enumerated current committee issues, including leadership and budgets, followup strategies in access to treatment, new standards of care, pilot demonstrations testing feasibility and efficacy of financing early access to new therapies, priorities for care and service, HIV/AIDS and episodic disability, pharmaceutical cost reduction, Native American issues, the new White House Advisory Council on Consumer Protection and Quality in Health (members were asked to suggest HIV advocacy candidates), marijuana for medical uses, and youth.

Of particular concern is budget adequacy in vulnerable areas such as HOPWA, Ryan White, ADAP, and Medicaid, and the committee will follow up on the President's actions concerning these programs. Given the importance of the issue of managed care for all people with chronic disabilities, the committee will monitor its impacts and develop recommendations for submission to the Administration. Also under consideration for recommendations are military clinical trials, international access to treatment, and HIV prevention in youth. A Leadership recommendation based on 1998 budget considerations was presented by the Services Committee and approved by the Council (see New Recommendations section below).

Native American issues presented by the Services Committee were obtained by Mr. Bollman and Ms. laFavor from leaders in the Native American community, the National Native American AIDS Prevention Project, and representatives from SPNS and involve categorical services and funding to the community. Because they are classified as Sovereign Nation, Native Americans are often neglected by national programs: under Ryan White reauthorization, annual allocations to Native Americans have been reduced, and SPNS funds have decreased. Other problems concern the cultural appropriateness of Government programs; questions about the quality of an SPNS project created to ensure that medical services to Native Americans remain at a high level and that the community be included in research grant work; and the lack of focus on this population in the past by such groups as ONAP. Assuring the Council that they did not want to "micromanage" or suggest specific funding and other activities within the Government but rather force an analysis of the intent and impact of the Ryan White Act (part f), the committee proposed a series of recommendations on Native American issues (see New Recommendations section below). A letter of request will be sent to ONAP regarding its upcoming national policy meeting on AIDS in the Native American Community, to invite representatives of PACHA; national, regional, and tribal American Indians; Alaska and Hawaiian Natives; Native American AIDS activists from urban, rural, and tribal communities; tribal officials; consumers; and representatives from Indian Health Service, HRSA, CDC-AIDS Division, and Bureau of Indian Affairs.

The Services Committee also presented recommendations concerning access to treatment (see New Recommendations, below). It was suggested by Rabbi Edelheit that the Council look to developing a definition of "disability," and Mr. Bollman said that the Services Committee will try to propose a recommendation on this issue for the next meeting.

Research Committee Report

The Research Committee met on December 15 and in a joint session with the Prevention Committee on December 16, with Dr. Levine, Chair; Dr. Cade, Ms. Greenberger, Mr. Hattoy, Dr. Hitt, Ms. Fraser-Howze, Mr. Johnson, Ms. Miramontes, Ms. Thurman, and Dr. Weniger were present.

Dr. Levine presented a letter drafted by Dr. Cade to Secretary Shalala expressing PACHA's views on needle exchange and referring to the body of scientific proof that needle exchange prevents transmission without increasing drug use. Rationale for sending the letter at this point is the critical time factor, given the Congressional mandate to the Secretary to answer questions regarding syringe exchange by February 15. Dr. Levine stressed that it must be made clear that needle exchange is only one component of a comprehensive prevention strategy. The letter was approved, with corrections and one abstention, to be sent to the Secretary immediately.

Dr. Levine summarized information given in the panel presentation on issues of ethnic and gender biases, inner-city poverty, and deterioration of communities, as follows:

Dr. Judith Auerbach, Behavioral and Social Preventive Science Coordinator for the OAR, discussed new NIH prevention science activities that grew out of the Working Group Evaluation Program. OAR will help create a prevention science agenda that equals those of other scientific research. OAR has also allocated $6 million for the behavioral agenda, and a working group was established to identify the spending priorities and long-term HIV prevention strategies and service plans. The relevant disciplines include demography, anthropology, economics, medical geography, psychology, psychiatry, social ecology, sociology, history, political science, and neuroscience—disparate fields that need to be brought together.

Dr. Cynthia Gomez, Clinical Psychologist, Center for AIDS, University of California San Francisco, spoke of her research, which relates to gender, racial, and ethnic issues and behavior. Statistics show a preponderance of AIDS cases among four ethnic groups in the national population: Latinos/Latinas, 17 percent (9 percent of the U.S. population); African Americans, 32 percent (12 percent of the population); Asians/Pacific Islanders, 0.7 percent; and Native Americans, 0.2 percent. White/non-Hispanics constitute 50 percent; however, the trend in new infections is shifting even more toward minorities. Dr. Gomez also mentioned that the lesbian population, not considered a minority, has a higher seroconversion rate than heterosexual women. Distinct characteristics contribute to behavioral factors in each minority group, and intervention must take into account the ethnic culture factors. Education and knowledge are insufficient for effecting behavioral change; other necessary components are motivation, efficacy and skills, modeling, access to resources, and social factors.

Dr. Gomez' recommendations include the following: (1) target specific vulnerable populations, such as young African-American gay men, and log the risk behaviors in these groups in order to obtain funding for research and intervention; (2) try to determine whether newly infected individuals took part in early intervention programs to evaluate current efforts; (3) seek funding for qualitative data/research in such areas as sex habits; (4) monitor and offset the current perception that HIV/AIDS is now curable and the possible serious impact on prevention; (5) link family planning activities to prevention; and (6) devise models to empower affected communities.

Dr. Mindy Fullilove, Research Psychiatrist, New York State Psychiatric Institute, Columbia University, spoke of broader prevention issues, particularly the geography of AIDS. It is an "epidemic of place." For example, Harlem, South Bronx, San Francisco, Miami, and Puerto Rico are also the sites of other social epidemics such as TB, crack abuse, and violence. As inner cities are being "deconstructed," the loss of homes equals loss of security, consistency, self-esteem, and hope. For example, 30 percent of housing in Harlem has been lost in the last few years, leading to alienation and the breakdown of structures that enhance empowerment. Heroin shooting galleries and crack houses, where social norms break down and the spread of HIV becomes rampant, have been established in their place. This relates significantly to prevention, but funding has not been made available in the AIDS community for research in this area.

The consensus of the joint committees based on these discussions is that the Council must be very aggressive in pushing behavioral issues to the forefront of the epidemic. Recommendations of the Institute of Medicine, OAR, and NIH reports can act as models, and the two committees will develop specific recommendations on needle exchange, vaccine development, and substance reduction. A new National Institute of Mental Health (NIMH) report on how to sell behavioral and social science to communities and prove to other "hard" sciences that these are critical, interrelated issues will be reviewed.

On vaccine issues, the committee continues its self-education program, with information obtained both domestically and internationally, from the NIH, foreign organizations, and industry and community sources. Because one institution alone cannot cope with the vaccine problem, the committee is developing a mechanism to coordinate many groups, similar to the Vice President's Keystone Conference. A roundtable discussion should determine where we are in treatments, vaccines, and microbicides—issues not included in the last Keystone session. The agenda should also include liability and incentivation, sharing information among constituencies to determine current needs and redundant efforts and how to move forward. Funding is needed to administer the group, with participants paying part of that cost, and for implementation. Prior to the April meeting, the committee will have at least one more informational conference call and meet with Dr. Baltimore to develop proposals to be examined by outside experts.

Council members stressed that a vaccine has to be effective, accessible, and inexpensive, "belonging to the world." Rabbi Edelheit emphasized the inclusion of ethical issues in all recommendations—such as, the United States will not do this for a profit, especially in the international community—and suggested that the panel include clergy and other ethicists.

Report on Presentation of National Strategy on AIDS

The National Strategy on AIDS was presented to the President, Vice President, and the press on December 17, with Ms. Fleming, Dr. Hitt, Ms. Sanville, and Mr. Sorian in attendance. The President, Ms. Fleming said, is committed to this strategy and will do everything he can to implement it. Dr. Scott told the Administration that, although PACHA recognizes the significance of the document, other issues must be addressed, and the Council can provide input for this process.

Media interest is high, and Mr. Sorian was commended for his achievement in this area. Ms. Fleming and Dr. Scott were interviewed on CNN and Fox Networks, and many newspapers, including the *Washington Post* and the *San Francisco Chronicle*, ran major stories on the Strategy. Ms. Fleming said that ONAP would broaden its circulation to include African-American, gay, and lesbian media. The Strategy will be available on the Worldwide Web, and the National AIDS Clearinghouse (1-800-HIVAIDS) will provide free copies in bulk to PACHA and ONAP. (Members should contact Mr. Sorian or Ms. Sanville.)

With the current opportunity for implementing a nationwide program, members are encouraged to suggest areas for distribution and to talk about the National Strategy on AIDS within their own communities. Of concern are issues not covered and the need for a broader statement showing that the Strategy includes much more than needle exchange, the area most cited by AIDS activists and the press. It is important that members discuss Council recommendations and emphasize that the most important part of this process is implementation and what can be done. A "National AIDS Strategy Talking Points" paper was developed for this purpose.

New Business

PACHA and Government Transition: With many "friendly" staff members leaving ONAP and the White House, Council members were urged to suggest candidates and job description for these upcoming vacancies, as well as appointments to such agencies as the Federal Drug Administration (FDA), to ensure strong advocacy for continuing AIDS work. Suggestions should be given to the Process Committee, which will forward these to appropriate agencies. The Council should be involved in educating not only new ONAP staff, but White House and other personnel as well, and the Process Committee will develop an educational strategy and discuss appropriate lines of communications with the Administration. Currently, the two main contacts at the Office of Domestic Policy are Bob Nash and Peggy Clark.

On **Member absenteeism** Dr. Hitt said that the Administration will check attendance charts and ask nonattendees to step down to allow new, potentially more active, people to join PACHA.

New Council Recommendations

New recommendations to the Administration approved by the Council during the meeting are:

Leadership (Services Committee)

- That in his FY 1998 budget request, the President continue to protect Medicaid and Medicare, and seek increases in funding for research, prevention, care and services—including the Ryan White Care Act and HOPWA. *In particular, because of the availability of new drug therapies, ADAP funding must be increased, and not in competition with funding for the care system. Increased funding will be essential until new financing systems can be developed among private and public health payers to cover the cost of the new therapies. In the international arena, the President should seek increases in funding for USAID programs relating to the global epidemic.*

Inmate Discharge Planning (Prison Issues Committee)

- The Administration should direct the Secretary of Health and Human Services to develop oversight language appropriate for discharge planning (including accessing benefits) for ex-offenders with HIV/AIDS, designed to assure their continuity of care through Probation Departments in various locales as well as the accessibility of appropriate linkages within the community.

Native American Issues (Services Committee)

- Therefore, the Council requests that the President instruct the Secretary of Health and Human Services to reassess the legislative intent of the reauthorized Ryan White CARE Act regarding needs of the Native American community to ensure appropriate support for Native American care, infrastructure development, and coordination *on a national level*.

- Therefore, the Council requests that the Secretary of Health and Human Services instruct the Director of Indian Health Services to demonstrate within 90 days the adequacy of HIV prevention, care, and treatment, including access to needed drugs, for American Indians and Alaska Natives living on or near reservations. This should include documentation of needs assessments completed, barriers, gaps identified, and proposed solutions. It should also include a discussion of how IHS plans to work with the private nonprofit sector to improve AIDS-related services.

- Therefore, the Council requests that the Secretary of Health and Human Services instruct the Director of IHS to develop Case Management oversight guidelines appropriately oriented to the specific needs of Native American people with HIV/AIDS and assure the provision of health care in a safe and culturally appropriate manner.

Access to Treatment (Services Committee)

- That the Administration take the lead in working with the States and the private sector to reduce the cost of pharmaceuticals to ADAP and Medicaid programs.

- That the Federal government, working with the States, expeditiously develop, initiate, finance, and evaluate new demonstration projects that (1) enable funds to be used for very early access to HIV care services, and (2) assess the resulting impact on health status, life expectancy, client return to work and earned income, and net health care costs (new expenditures offset by lowered costs), on a lifetime and annual cost-of-care basis. These demonstrations should be conducted within both Medicaid and the Ryan White CARE Act, and should be financed with new funds, so as not to diminish access to care and treatment under current funding.

- That the Office of National AIDS Policy create a mechanism for the public sector, the private sector, and the community to engage in a formal, facilitated dialogue process on how to set priorities for HIV care and services that assumes the best use of resources and

recognizes a context of shifting demands for services. This dialogue should be completed within 6 to 8 months.

- That the Office of National AIDS Policy work with the Secretary of DHHS and the Secretary of Labor, the co-chairs of the Advisory Council on Consumer Protection and Quality in Health, to ensure inclusion of the concerns of people living with HIV in their recommendations.

Vice President--Prevention and Pharmaceutical Companies (Services Committee)

- That the Vice President continue the dialogue that he has established with the major manufacturers of HIV/AIDS drugs and that the issue of international provision of basic medications for the prevention and treatment of opportunistic infections and other HIV/AIDS-associated medical conditions be added to their agenda.

In discussing this recommendation, members pointed out that the larger "disincentives" among industry for prevention-type modalities, such as microbicides and vaccines, had been dropped from the initial Keystone agenda. This thrust should be made at a future working group, and as background, the Council will ask the Administration—through DHHS—for an accounting of NIH expenditures by institute and type of spending.

Future Business

The next Council meeting will be held April 5-8 at the Watergate Hotel in Washington, DC. The Ad Hoc Process Committee, comprising the chair or one other member of each of the working committees, will address the following issues for the meeting:

- Development of panel presentations on vaccines and substance abuse, with three or four key people discussing background and recommendations, and a possible third panel on African-American issues.
- Development of an ad hoc committee to investigate minority cultural and political issues, with Ms. Fraser-Howze and Mr. Burgos as co-point persons. The Process Committee also will address questions as to how many committees or working groups are feasible for the Council and how issues that concern one or more committees should be handled.
- Ensuring that committees have more time for meetings, especially if scheduled at lunch, and that there are appropriate breaks throughout the sessions.
- Scheduling meetings and facilitating logistics to accommodate members of multiple committees. Members should inform Mr. Montoya as to which committees they will serve on so that a full list can be submitted prior to interim conference calls. If scheduling conflicts arises for multi-committee members, they are urged to submit input on pertinent issues during calls.
- Ms. Fleming was invited to attend the meeting for a formal presentation of the Council's gratitude for her service to ONAP and PACHA.
- New recommendations should be submitted to the Process Committee at least 14 days prior to the meeting, so that they can be sent out for member preview.

- Requests for committee conference calls and for information from outside sources should be sent to Mr. Montoya. A request by Mr. Anderson that the SSA be asked to report on implementation of changes in disability requirements around substance abuse and how this is being monitored was approved, and Mr. Montoya will handle the request.

Dr. Hitt thanked Council members, committees putting together panels that "set standards" for such presentations in the future, and ONAP staff for their participation. The meeting was adjourned at 1 p.m. December 17, 1996.