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Talking Points
Presidential Advisory Council on HIV/AIDS
November 16, 1998

Sandra L. Thurman

- Welcome
- Acknowledgments
 - Scott and Daniel
 - Matthew Murguia
 - Todd
 - Interns – Kelli Stewart and Emily Seymour
 - PACHA Members
 - Work on Strategic Plan – gotten more focused
 - Interim activities since last meeting
- Major issues to cover in these comments and over next few days:
 - Congressional Black Caucus Initiative
 - FY 99 and 2000 budgets
 - Impact of November Elections
 - Update on 1996 Youth Report/Presidential Directive
 - World AIDS Day (though planning is still underway)
 - December Meeting with the President
 - Other progress on PACHA's recommendations
- Very exciting and interesting meeting ahead, including:
 - Surgeon General's update on the Race/Health Initiative
 - Update on Needle Exchange
 - Ryan White reauthorization
 - New directions for CDC from Dr. Koplan
 - Presentation on American Indians, Alaskan Natives and Native Hawaiians (thanks to Charles Blackwell for his work on this issue)
 - Treatment access
 - Special thanks to Daniel and Council on developing such an ambitious and focused agenda for this meeting and for all the hard work in preparing for this meeting

Congressional Black Caucus Initiative (SLT)

- President declared HIV/AIDS a “severe and ongoing health care crisis” in the African-American and minority communities
 - He announced \$156 million in AIDS-related funding for minority communities
 - Copies of White House press briefing paper and the President’s speech in binder
- This was a huge success, and came about because of a lot of hard work by a lot of people
 - Want to acknowledge Debra Frazer-Howze for her efforts
 - Representatives Waters and Stokes, and other members of the CBC
 - Representatives Pelosi and Porter, and Senator Specter – appropriators
 - Secretary Shalala, Deputy Secretary Thurm, Surgeon General Satcher, Dr. Goosby and others in HHS
 - Maria Echaveste, Minyon Moore here in the Administration
- Political importance of initiative
- pleased to see this money added, but it is not enough to solve the problems in minority communities and that more needs to be done
- very pleased about the organizing that came about through this advocacy effort –
 - mainstream political groups
 - NAACP – went with Vice President to Atlanta meeting
 - SCLC – did presentation to leadership
 - CBC – President addressed issue, Todd and I attended their annual meeting
- concerned that we don’t look at the \$156 million as the minority set-aside
 - this has to be about all of the discretionary dollars – over \$4 billion
 - making sure that funds follow the epidemic
- also need to look carefully at how the needs of African Americans, Latinos, Asians/Pacific Islanders, and Native Americans relative to HIV/AIDS are integrated into the broader discussions of race and health
 - Dr. Satcher will tell you more about the Race and Health Initiative – very important to remain connected with that broader effort
- Great deal of work left to do
 - Implementation – again, Drs. Satcher and Goosby will have key roles
 - Look at how we can address particular needs of African Americans, but also broaden discussion to other racial and ethnic minorities
 - Need to put the “meat on the bones” of the \$156 million and, more importantly, how we

change the way business is done

- Follow-up with other Congressional groups
- Rep. Waters committed at the Dallas conference to work with the Congressional Hispanic Caucus, the Asian Caucus and others to push through a similar effort for these populations
 - While she initially did not mention Native Americans in her remarks, she returned after her speech to specifically mention Native Americans.
- We all need to take her up on her offer of joining with other groups to secure similar funding for other communities of color
 - Todd and I have already started working the inner halls of the White House to try and do just that
- Thank again everyone who attended the White House event regarding the announcement
- Acknowledge Denise Stokes' remarks
- considering how this was the Council's number one priority, you all should take heart that your efforts do work

The FY 99 BUDGET (TS)

- this has been an extraordinary year for AIDS funding
- historic increases pretty much across the board, even before CBC funding
- secured nearly ½ billion dollars in new funds within the constraints of a balanced budget
- information about the FY 99 budget in your packet
- Highlights:
 - \$261.4 million in new funding for Ryan White, a 19% increase
 - including 70% increase to ADAP
 - 10% increase in NIH's AIDS research budget
 - An additional \$32 million in prevention funding, a 3.5% increase
 - 19% increase in SAMHSA's budget -- finally
 - nearly 10% increase in HOPWA funding – special work of Administration to get \$10 million
- Also had some challenges in the budget:
 - DC needle exchange amendment
 - Continuation of needle exchange restriction
 - Little increase in international funding

The FY 2000 Budget

- Begun dialogue with OMB over the FY2000 budget
- We are pushing for substantial increases across the board
 - With Ryan White, seeking to balance need for additional ADAP funds with recognition that primary care and supportive services remain critical
 - Big push on prevention funding, with an emphasis on
 - increasing HIV testing by at-risk populations
 - access to care for those who test positive
 - better integration into STD, maternal and child health and other related efforts
 - Asking for additions to SAMHSA funding for drug treatment and prevention, particularly for youth
 - More money for HOPWA

- Overall, we are recommending that any new funds:
 - be targeted
 - that we are very clear about our expectations for their use, and
 - that we focus on addressing minority and youth populations in areas where funding and need are not proportional

The Elections/Change in House of Representatives Leadership (SLT)

- I am not sure yet what it means for AIDS issues, but the change in leadership in the House of Representatives, with the Departure of Newt Gingrich and the apparent assumption as Speaker of the House by Congress Robert Livingston of Louisiana, is likely to have profound impact on AIDS programs
- Congressman Livingston is chair of the very powerful House Appropriations Committee
 - He has been largely supportive of AIDS funding issues
 - he helped ensure the major increases we received in FY 99
- With his move to the Speakership, it remains to be seen who will be selected as chair of the Appropriations Committee and what they think about AIDS issues, as well as who will be elected to the other important leadership positions within the House
- Regardless, our job is to forge a new working relationship with whomever takes over the Appropriations Committee and work with them to ensure that they understand the needs of people with HIV and the importance of prevention and research

Youth Issues (TS)

- We have been working on a variety of issues related to youth
 - Starting the review, as you have requested, of the 1996 Youth agenda
 - Working to collect responses to the President's Executive Order of last World AIDS Day
- Started work on integrating the two processes
 - for example, we've cross-walked the inventory of programs obtained through the Executive Order with the recommendations in the 1996 agenda
 - trying to do combined report
- Matthew has been spending a lot of time on this – thanks
- We have not been thrilled with the responsiveness – not going to be earth-shattering
 - Most Department's will doing the following types of things:
 - Sending letters to all their grantees asking them to coordinate efforts with local ASO and CBOs
 - Asking grantees to put point-of-service displays in public areas of their offices/facilities
 - Developing specific mailings/newsletters focusing on HIV and youth for distribution to all clients
 - single out Selective Service Administration for mailing
- Sandy and I are working on getting the President and Vice President to do youth-oriented events this coming World AIDS Day to give issue elevated attention
 - Hope to be presenting report to the President on World AIDS Day
 - Working with Council members and others in community to continue our efforts, develop new ideas, and obtain support for them
 - Using WAD and the President's event to drive a few new initiatives focusing on at-risk minority youth that we cooked up

December 19 Meeting with the President (SLT)

World AIDS Day (TS)

- December 1
 - This year's theme is "Be a Force for Change," and is focused on youth, 13 – 21
 - Matthew has been working with the Federal Departments to encourage each of them to develop specific World AIDS Day observances
 - Also brought up at the meeting of Chiefs of Staff, convened by our Cabinet Affairs office
 - This year, several things will be happening that are worthy of noting, including:
 - As Todd mentioned, we have asked that the President meet with a small group of youth to discuss youth-specific issues. We have asked for approximately 30 minutes, including 5 minutes of comments by the President that will be open press
 - Vice President will likely be making some announcements related to both youth and AIDS housing funding
 - I will she be doing some events to hopefully garner some press coverage of the issue including a visit to a local school that may be covered by MTV and the Ricki Lake show
 - White House will be dimming its lights
 - Each Federal agency, for the first time, will have a message on World AIDS Day either printed on their pay stubs or provided via electronic mail or desk to desk memorandum
- "More than 50% of all new HIV infections are in youth under the age of 25. Have you talked with your loved ones about how to prevent HIV infection. Call 1-800-458-5231 to find out how."
- We also plan on doing a press release listing out all Departmental activities for World AIDS Day, as has been done in the past

Other Issues and Progress (SLT)

▪ **HIV Vaccines**

- Extraordinary focus by Dr. Nathanson
 - Devoted entire meeting of OAR's advisory council to this issue
 - Has noted it as one of his top priorities in interviews (copy of JAMA interview was sent out to Council)
- Gotten commitment by Dr. Nathanson to go ahead with semi-annual vaccine coordination meetings
 - Rotate through NIH, CDC, and Defense – possible USAID
 - Host will do more extensive report on their activities
 - Open meetings – government, private industry, and advocates
- President is keeping abreast of this issue

▪ **Prisons**

- Todd hosted meeting with HCFA, HRSA, Justice and Bureau of Prisons to talk about post-incarceration services
 - Outlined problems and discussed several potential solutions
 - Need to continue work on this area
 - Work is difficult
- Gotten Justice to work with us on a national meeting – we will be working with Prisons Committee members to set a date
- Todd worked a lot with OMB and Justice on the Correctional Officers Health and Safety Act, which passed, to improve it significantly – still not great, but vastly improved

▪ **International**

- Hosted a meeting of the World Bank, representatives from India, and about 15 NGOs
 - talked about India's new AIDS Control Program and the pending World Bank loan that will help fund it
 - One of the first of this kind of meeting
 - Hope to do more
- Got Vice President to send letter to Deputy President Mbeki congratulating him on a national speech on AIDS, offering my services to his government
- Going to India in December for UNAIDS meeting
- Working on an AIDS orphan initiative – still very preliminary

Concluding Comments (SLT)

- With Dr. Mann's death, we need to help carry the torch on helping others to see AIDS as a human rights issue
- The easy part is over – no more flash in the pan responses
 - Issues are complicated
 - Do not lend themselves to easy solutions
 - Political environment will get more complex as we approach the Presidential election
- We need to think about more long term solutions and moving some support for AIDS into non-AIDS specific programs
- Need to become better and more active partners with others in supporting critical legislation
 - Patient Bill of Rights
 - Jeffords-Kennedy
 - Whatever privacy bills are developed
- Think carefully about your role
 - How to be most helpful and productive
 - Can't just be a stick

ONAP RESPONSE - November 16, 1998

LEADERSHIP

IX.L.1 On April 20, 1998, the Secretary of Health and Human Services made a determination that needle exchange programs can be an effective part of a comprehensive strategy to reduce the incidence of HIV transmission and do not encourage the use of illegal drugs.

However, the restriction on the use of Federal funding for needle exchange programs--imposed by Congress--was not lifted. The Administration decided that the best course of action is to have local communities which choose to implement their own programs use their own dollars to fund needle exchange programs.

The decision not to exercise the authority provided by Public Law 105-78 to lift the restriction was made to reduce the likelihood of threatened Congressional action that would have rescinded that authority and imposed additional restrictions. In the interests of protecting the over 100 extant needle exchange programs and forestalling a negative political response, it was decided to allow for the determination of the scientific merits of needle exchange programs and maintaining the funding restriction.

Since that time, the Administration has opposed efforts to remove the Secretary's authority in this area, arguing that the decision should remain in the hands of public health officials and not politicians. In addition, the Administration vigorously opposed an amendment to the DC Appropriations bill that restricted the use of local funds for needle exchange programs, and that barred Federal funds from going to any entity that operated needle exchange programs.

The Administration remains committed to working with State and local officials and communities to understand the scientific support for the efficacy of needle exchange programs in reducing the spread of HIV. In addition, the Administration will work with Congress to obtain support for drug treatment, HIV prevention outreach, and other activities that would help reduce the spread of HIV among injection drug users, their partners, and their children.

ONAP RESPONSE - November 16, 1998

IX.L.1.a The Administration, working with key members of Congress, was able to obtain historic increase in AIDS funding. They include the following highlights:

- Over \$260 million increase for the Ryan White CARE Act, a cumulative increase of over 280% since the President took office;
- An increase of over \$175 million in the AIDS Drug Assistance Program, which helps States pay for AIDS therapies for those that cannot otherwise afford them;
- A \$21 million increase in HOPWA, which helps provide housing for people living with AIDS;
- \$32 million more for HIV prevention at the Centers for Disease Control; and
- \$185 million more for AIDS research at the National Institutes of Health.

ANALYSIS OF FY99 BUDGET SELECTED AIDS PROGRAMS	1999 Enacted	% Change 1998 to 1999	% Change from 1993
HRSA - Ryan White (HHS)			
Title I	505,200	+ 9%	+ 173%
Title II (excluding ADAP)	277,000	+ 8%	+ 140%
Title II (ADAP)	461,000	+ 61%	+ 787%
Title III (Early Intervention)	94,300	+ 24%	+ 97%
Title IV (Women, Children, Youth)	46,000	+ 12%	+ 120%
Dental Services	7,800	+ 0%	
AIDS Education Training Centers	20,000	+ 16%	+ 18%
Health Professions Act or equiv.			
Subtotal	1,411,300	+ 23%	+ 266%
CDC (HHS)			
HIV Prevention and Education *	657,000	+ 5%	+ 34%
SAMHSA (HHS)			
HIV set-asides	86,622	+ 58%	+ 238%
NIH (HHS)			
AIDS Research	1,792,916	+ 12%	+ 67%
HUD			
HOPWA	225,000	+ 10%	+ 125%
TOTAL	\$ 4,225,821	+ 16%	+ 103%

ONAP RESPONSE - November 16, 1998

PREVENTION

VI.P.1 ONAP believes that the current process for review of HIV prevention materials by citizen review panels has not proven to inhibit the delivery of effective, direct prevention messages. At this time, opening up a discussion on this process may well result in the imposition of more restrictive standards and procedures. Therefore, ONAP recommends that the PACHA rescind this recommendation.

**R. Scott Hitt, MD
Talking Points for the
Presidential Advisory Council on HIV/AIDS
Monday, November 16, 1998**

- **Welcome the Council and other guests (recognize any prominent attendees)**

Much has happened since we last met as a full body this past June, including:

- 12th World AIDS Conference in Geneva in June
- US Conference on AIDS in Dallas in October
- as well as other countless meetings, conferences, etc.

- **DEDICATION OF MEETING TO JONATHAN MANN AND MARY LOU CLEMENTS-MANN**

Dedication: This Council meeting is, as always, dedicated to all people living with HIV/AIDS and affected by this disease, and all those whom we have lost. We especially seek to provide a voice for those who are most vulnerable to this epidemic, including other epidemics in this world that prohibit a person to adequately address their health such as lack of housing, lack of education, discrimination, stigma, starvation, etc. I would like to especially recognize the lives of Drs. Jonathan Mann and Mary Lou Clements- Mann. Both were tireless champions of people infected and affected by HIV/AIDS. Dr Mary Lou Clements-Mann, among many accomplishments, was a professor at John Hopkins School of Hygiene and Public Health University and principal investigator in NIH AIDS Vaccine Evaluation Unit network as well as having had extensive experience in the clinical R& D of vaccines for other human diseases. Dr. Jonathan Mann was the Dean of the School of Public Health at Allegheny University of the Health Sciences. He, too among many other accomplishments, was the Founding Director of the Global Programme on AIDS at the World Health Organization and Founding Director of CDC's Project SIDA in Kinshasa Zaire, which was the world's first field research station in Africa devoted to HIV/AIDS. It was in Zaire that he first defined the relationship of health as a human right. He continued to speak out, most recently with us in March of this year, where he again pointed out the correlation of health as a human right and voiced his opinion for wide scale clinical trials of AIDS vaccines.

We have suffered the loss of remarkable human beings who dedicated their lives to those who have had to deal with this horrible disease and for

that we are truly humbled and grateful. I ask you to pray for their families as you remember them and others who have fought tirelessly for all those who live with HIV/AIDS and are affected by this disease.

I especially ask that you remember that we do not work in a vacuum when we deal with HIV/AIDS health care policy. That we, in fact, have worked to ensure that this Administration recognize the connection between housing and HIV/AIDS, between discrimination and HIV/AIDS, between homophobia and HIV/AIDS, between, lack of education and HIV/AIDS and the connections could go on and on. Let me leave you with this quote from Dr. Mann as he addressed AIDS Action Committee Dinner in Boston in 1988, all of which is still true today, and probably more evident:

"In the last few years we have gained confidence that as individuals and all together we are not condemned passively to allow the disease AIDS or the fears and forces which it can unleash to dominate us. Against AIDS we will prevail together, for we will refuse to be split, or to cast into the shadows those persons, groups and nations that are affected."

I would only add that we as a Council must continue to strive for what we can achieve in the short amount of time that we have together. We should remember that we will not be able to solve all of those social ills that infect and affect HIV/AIDS, but we will continue to provide a voice for positive change so that we may bring a better quality of life to those who so desperately need it and more importantly demand it.

• **Notes of Council member activities**

- Mention: Kathy Gerus' movie release "An Everyday Eulogy" premiering December 8th at the Star John R. Theater in Madison Heights, Michigan
- Thank Debra Fraser Howze, Alexander Robinson and Ron Johnson for their involvement with the Congressional Black Caucus and the recent roll-out by the President, Secretary and Surgeon General regarding appropriations targeting the "severe and ongoing health crisis" in the African American community and the beginning of addressing other racial and ethnic populations.
- **CHANGES IN Subcommittees:** Thank you to Nick Bollman for his leadership as Services Subcommittee Chair and Regina Aragon and Tom Henderson willingness to take on the leadership of the Services

Subcommittee as co-chairs

- Recognize Ron Johnson for his leadership role as Interim Acting Director of GMHC (Dr. Joshua Lipsman named new director) and his continued participation with International issues, especially his help with the recent Congressional hearing regarding the GAO report on UNAIDS funding and its favorable outcome for continuation of that funding.
- **Professional Changes:**
- Recognize: Stephen Abel's new position as "Oral Health Policy Liaison" with the New York State Department of Health/AIDS Institute
- Recognize: Terje Andersen's new position as Deputy Director of Policy at NAPWA
- Recognize Ben Schatz, impending departure as Executive Director of Gay and Lesbian Medical Association and his new journey with the "Kinsey Sicks"
- Recognize Sean Sasser's new role as Executive Director of HIFY in San Francisco.

- **Introduction of ONAP Staff**

- Matthew Murguia from the Office of Minority Health (**attending**)
- Sandy's Executive Assistant - Sarah Holewinski
Mary May, receptionist
- Thank Sandy and Todd for their tireless work and their commitment to the needs of people living with HIV/AIDS.

- **Acknowledge attendance of new White House Interns**

Emily Seymour, University of Pennsylvania
Kelli Stewart, University of Utah

(Both of them have also worked long hard hours to provide the necessary assistance to ONAP as well as PACHA)

- **SSS Staffing/Changes**

(Let Daniel talk about changes at SSS including our new direct liaison Andrea Hall and the promotion of Ann Borlo).

- **ROLE OF THE COUNCIL**

(As done during almost every one of the preceding meetings, remind the Council of their role)

Provide **ADVICE, INFORMATION AND RECOMMENDATIONS** regarding **PROGRAMS AND POLICIES** intended to **PROMOTE EFFECTIVE PREVENTION** of HIV Disease; advance **RESEARCH**, as well as promote **QUALITY SERVICES** to people living with HIV/AIDS

We are **SOLELY ADVISORY IN NATURE**.

We **CANNOT LOBBY** for specific legislation.

- **ROLE OF CHAIR OF PACHA**

To provide leadership in the direction of the Council

Help maintain focus of efforts

Help, along with each of you, to place a reality check on our efforts and recommendations.

This does not mean we don't push the envelope, it just means we do it in the right way at the right time on the right issues.

- **ROLE OF THE EXECUTIVE DIRECTOR**

(Let Daniel speak for himself about his role and what he does for the Council)

- **PACHA STRATEGIC PLAN**

(Remind members that the focus of the June meeting was to agree on a small number of priority issues for the next year, and the strategies and structures to implement them. This Council's currently authorized tenure extends only through July, 1999, and the primary focus is on issues that could be either resolved or positively impacted within that timeframe.)

It is gratifying to know that already our voice has had an impact on some of these objectives and you will hear when Sandy talks, that there has been movement in some of these areas.

"Short-term Achievable" Priorities:

1. Work to advance the call for a State of Emergency in the African American and Latino communities through a variety of strategies, such as the following:

- Engage the President by requesting that he convene a special meeting with the Congressional Black Caucus and Hispanic Congressional Caucus to develop a strategy regarding the State of Emergency
- Call for a Special White House conference on the State of Emergency in communities of color

2. Influence CDC policies and programs related to HIV/AIDS prevention, including:

- Establishment of a youth initiative
- Ensure that the CDC establishes a national initiative to encourage testing that effectively targets high-risk populations
- Ensure that the CDC includes in its HIV Prevention Community Planning guidance language requiring that use of community prevention funds be linked to the local demographics of the epidemic, and that the CDC evaluates compliance with the direction in the guidance

3. Track and advocate for access to care and funding for early intervention through expansion of Medicaid, working at the national policy level (HCFA and the White House) and with regard to State waiver applications

4. Work for higher appropriations for HIV/AIDS prevention, services, and research, including the following:

- Support NORA's FY 1999 HIV/AIDS appropriations request
- Develop an appropriate strategy for 2000 appropriations
- Focus on increased funding for substance abuse treatment, building service capacity in communities of color, youth, and international HIV/AIDS programs

5. Provide input to the new international strategic plan on HIV/AIDS being developed by the Department of State and help ensure that its provisions are

implemented

6. Advocate for attention to women-centered prevention methods (microbicides)

[Language of recommendation to come by November]

PACHA's NOVEMBER AGENDA HIGHLIGHTS

We have a full agenda and I'm not going to go into great detail because I want to hear from Sandy about all that is happened but let me just mention some highlights since we last met:

- **Elections**

Mention recent local, state and federal elections, especially change in House leadership, and the ramifications of those in office on HIV/AIDS health care policy, especially Congress as it deals with upcoming FY 2000 appropriations and legislative issues such as Ryan White Care Act Re-authorization.

- **Racial and Ethnic Minority Populations**

"State of Emergency" or as it is now referred to as "Severe & Ongoing Healthcare Crisis"

The President, working with the Congressional Black Caucus, appropriated \$168 million in AIDS-related funding for minority communities with an emphasis on the African-American community. We as a Council need to work to ensure that this is the beginning of new monies appropriated to racial and ethnic populations and that we continue to see a focus by the Administration to address all the needs of these communities because you can't address health care without addressing housing, education, etc. and you can't address access to health care without addressing all those who fall between the cracks.... Mention (below).....

Full Council Presentation: "Disparities in HIV/AIDS Health Programs for American Indians, Alaskan Natives and Native Hawaiians" Thank Charles Blackwell for his work in putting this panel together.

Full Council Presentation: Dr. Satcher is presenting to the full Council, tomorrow. I am very impressed by his willingness to work with this Council, not only in the work that some members that I have already mentioned have had in bringing about this appropriation, but his willingness to meet for a second time in less than six months to update us on his efforts.

- **Appropriations**

The Council sent two letters to the President regarding Appropriations for FY 1999 and

FY 2000. A copy of those letters are in your briefing books as a reference. (Sandy will talk more in depth on this.)

- **Prevention**

Needle Exchange: Where do we go from here....Good news/Bad news. The good news is that the Administration finally certified the science behind needle exchange programs, but the bad news is that there is no federal funding for any needle exchange program. Marsha Martin, Special Assistant to Secretary Shalala will be giving us an update from HHS' perspective. Remind the Council that we are dealing with a Congress that is not receptive to any efforts to provide federal funding for needle exchange programs and it was very evident during the 105th Congress and the DC Appropriations process. The Council also sent a letter to the President regarding our continued frustration with their inability to federally fund needle exchange programs. We echoed our commitment to continually ensure that substance abuse, and that includes needle exchange, is addressed, especially since the number of new infections in racial and ethnic populations are disproportionately impacted by intravenous drug use and the sharing of "dirty" needles.

Full Council Presentation: Dr. Jeffrey Koplan, new CDC Director will present to the full Council, tomorrow (Tuesday) and will provide us his focus for prevention, especially as it relates to HIV/AIDS. We will be asking the director some questions about his role and his hopes for CDC. If you have any statements/questions that you wish to ask the director, please make sure that you get with either Mike Isbell, Alexander Robinson, Daniel Montoya or myself so that we can put all the questions into the mix and provide the director with our thoughts on what is important as he begins his tenure as CDC director. (Mention that the Exec. Sub. is meeting for lunch as a group to finalize all questions that the Council will ask Drs. Koplan and Satcher, at noon today.)

- **Research**

AIDS Vaccine Initiative: Dr. Neal Nathanson was appointed as the new director of the Office of AIDS Research (OAR) at NIH. On October 14th the OAR Advisory Committee met and provided an update on the AIDS Vaccine Initiative. Sandy and Todd will share more details when they speak.

Topical Microbicide Development Update: The Research Subcommittee has developed some recommendations. Drs. Zeda Rosenberg and Penny Hitchcock will

discuss the potential recommendations from this Council to the President during the Research Subcommittee meeting on Wednesday. Also, some of the \$158 million dollars toward racial and ethnic populations will be targeted toward topical microbicide research.

- **Prison Issues**

The Prisons Subcommittee is working on a potential recommendation from this Council to the President and will be visiting a prison facility to better gauge their work for incarcerated populations.

- **International Issues**

Nancy Carter Foster and David Wagner will be providing an update on the "US International Response to HIV/AIDS" draft report. They will present their update this afternoon to the International Subcommittee.

- **ENDING**

And on this note, I hope that I was clear when I spoke about Jonathan and Mary-Lou. You can't expect to address HIV/AIDS in one area without addressing it in all areas. We must remember that what we do in this country affects developing countries and what we do in this country for one population needs to be done for all populations regardless of the numbers, because it is about human rights and our continued struggle to ensure that we prevent new infections and provide quality access to health care for those who live with HIV/AIDS.

Thank all Council members for their continued work.

Recognize all those present in the audience and throughout the meeting and thank them. Encourage and Invite them to constructively push this Council to be a better voice for them.

NOTES FOR PACHA CONFERENCE CALL

October 14, 1998

Activities of the Office of National AIDS Policy

1. **CBC/AIDS in the African American Community** - worked with Administration and HHS officials to respond to CBC's call for a public health emergency - advocated for appropriate attention, POTUS and VPOTUS visibility (including sections of speeches), funding increase, and targeting - worked with community groups to obtain support for initiative; attended CBC town hall meeting and weekend events (accompanying Vice President to Atlanta and President to CBC)
2. **Kennedy/Jeffords** - worked to obtain support for disability demonstration program, and to make it a high priority for Administration in final negotiations on FY99 budget discussions
3. **Prisons issues** - made numerous contacts with Justice staff to obtain movement by BoP on requests by PACHA (including calls by SLT to Asst. Sec. Acheson) - set up meeting with HRSA, HCFA, and BoP/Justice on post-incarceration services problem
4. **Research issues** - veted idea of vaccine purchase fund - SLT and TS met with Dr. Nathanson - obtained approval of semi-annual coordination meetings, prioritization of research on women-controlled prevention methods, stressed importance of vaccine initiative; worked with OMB to address funding cut in DoD's vaccine research budget
5. **Prevention** - worked with CDC on targeting of funding, accountability, prevention conference, support for ONAP; worked with OMB and HHS on solidifying Administration's opposition to numerous bills expanding needle exchange funding restrictions (esp. amendment to DC approps)
6. **International** - met with World Bank re: India loan, set up community briefing on India loan and AIDS control program; met with International Committee of NORA; co-sponsored briefings by State Dept. on its strategy; worked with USAID and HHS on response to GAO report; met with representatives of a variety of foreign governments, including Australia, India, Netherlands, Vietnam, and Canada; drafted letter for Gore/Mbeki correspondence; attended Geneva conference
7. **Services** - held meeting of Treatment Access Task Force; arranged for briefing by HHS on analysis of Geneva data - follow-up briefing to Task Force requested; worked with HCFA on funding for skilled nursing facilities and problem of inadequate capitation rates for persons living with AIDS
8. **Appropriations** - supported Administration's position on FY99 budget negotiations, including advocacy for additional CBC-initiative funding; arranged for and accompanied

OMB examiners on trip to Boston - future trips to Philadelphia and Minnesota to follow;
worked on getting AIDS research number in NIH manager's report language

9. **Legislative review** - worked with OMB on a variety of legislative responses including HR2070 (Correction Officer Health and Safety Act), Hate Crimes Prevention Act, and DC appropriations, hollow-bore needle requirements,
10. **Substance Abuse** - had discussions with OMB and HHS on need to improve SAMHSA's attention to HIV/AIDS; participated in meetings of the Interagency Working Group on Demand Reduction (sponsored by ONDCP)
11. **Public Opinion** - participated in numerous media events, article interviews, and public speaking opportunities to improve public awareness of the scope and severity of the epidemic, and the Administration's efforts to address it
12. **Youth** - met with HHS several times to review responses from agencies; prompted re-submission by HHS through memo from Deputy Secretary; in process of reviewing 1996 report to obtain actions by World AIDS Day; spoke at DASH conference in Seattle
13. **Women** - held roundtable discussion of women leaders; doing follow-up on proposed recommendations by that group
14. **Other** -
 - worked with HHS and CDC on proposed HIV surveillance policy
 - worked on HOPWA cut
 - worked on human growth hormone funding problem at HCFA (Serrano)
 - SLT and TS went on vacations
 - arranged for PACHA meeting with POTUS
 - reviewed speech materials for POTUS and VPOTUS
 - reviewed AIDS-related correspondence from POTUS

Presidential Advisory Council on HIV/AIDS Eleventh Meeting

November 16–19, 1998

The Madison Hotel
Washington, DC

DRAFT AGENDA

		<u>Monday, November</u>
9:00 a.m.	Welcome R. Scott Hitt, M.D., Chair Update of Interim Activities Overview of Strategic Plan/Workplans	<i>Mount Vernon A & B</i>
10:30 a.m.	Office of National AIDS Policy Update Sandra Thurman, Director	
12:00 noon	LUNCH (on your own)	
2:00 p.m.	Subcommittee Meetings: Appropriations Subcommittee Subcommittee Discussion of FY 1999 and FY 2000 Budget International Issues Subcommittee Update on the "U.S. International Response to HIV/AIDS" by the U.S. Department of State Invited: Nancy Carter-Foster and David Wagner, U.S. Department of State Racial Ethnic Populations Subcommittee National Minority HIV Plan Invited: Matthew Murguia, OMH (2:00 p.m.)	<i>Drawing Room #1</i> <i>Drawing Room #2</i> <i>Mount Vernon C</i>
	Subcommittee Preparation for Presentation by Dr. David Satcher (3:00 p.m.) CDC's People of Color Initiatives Invited: Dr. Helene Gayle, CDC (Note: Prevention Subcommittee meeting on Tuesday, November 17, at 3:15 p.m.)	

Monday, November 16(continuation)

4:00 p.m.

Prevention Subcommittee

Drawing Room #1

Update on Needle Exchange Issues

Invited: Marsha Martin, Ph.D., HHS (4:00 p.m.)

Subcommittee Preparation for Full Council Presentation

by Dr. Jeff Koplan, CDC, and Discussion with

Dr. Helene Gayle, CDC (5:00 p.m.)

Services Subcommittee

Drawing Room #3

"Housing as an Access to Health Care Issue"

Presentation

Invited: Angela A. Aidala, Ph.D., and Joyce Moon
Howard, Dr.Ph., M.H., Columbia University School
of Public Health; and Robert Sember, M.A.,
Columbia University School of Public Health (4:00
p.m.)

"Massachusetts' State Medicaid Waiver Planning
Process" Presentation

Invited: Robert Greenwald, Boston AIDS Action
Committee (5:00 p.m.); Annette Hanson, M.D., MA
Division of Medical Assistance; and
Jeanne McGuire, MA State AIDS Director

6:00 p.m.

ADJOURN

Tuesday, November 17

Mount Vernon A & B

9:00 a.m.

Full Council Presentation "Disparities in HIV/AIDS Health
Programs for American Indians, Alaskan Natives and
Native Hawaiians"

Invited: Paul Bouey, Ph.D., National Native American
AIDS Prevention Center, and Daniel C. Simpson,
Indian Health Service

10:15 a.m.

BREAK

10:30 a.m.

Full Council Presentation "Update on the HIV/AIDS Racial
and Ethnic Disparities in Health"

Invited: Dr. David Satcher

12:00 noon

LUNCH (on your own)

2:00 p.m.

Full Council Presentation "Focus for the Centers for Disease
Control and Prevention"

Invited: Jeffrey Koplan, M.D., M.P.H., CDC

3:00 p.m.

BREAK

Tuesday, November 17(continuation)

3:15 p.m. Subcommittee Meetings:
Prevention Subcommittee Mount Vernon C
 Discussion on HIV/AIDS Prevention Issues
 Invited: Helene Gayle, M.D., CDC
Services Subcommittee Drawing Room #1
 Update and Discussion on Ryan White CARE Act
 Reauthorization
 Invited: Terje Anderson, Chair, HRSA AIDS Advisory
 Committee; David Harvey and Miguelina
 Maldonado, Co-Chairs, National Organizations
 Responding to AIDS; John Palenicek, HRSA; and
 Daphne Long Rankin, National Association of AIDS
 Education Training Centers
 Update on HRSA/Title IV Programs and Focus on Youth
 Invited: Wayne Saucedo, HRSA
Research Subcommittee Drawing Room #3
 5:00 p.m. **Appropriations Subcommittee** Drawing Room #1
International Issues Subcommittee Drawing Room #3
Racial Ethnic Populations Subcommittee Mount Vernon C
 HIV/AIDS Data Policy
 Invited: Dr. Olivia Carter-Pokras, OMH
 6:00 p.m. **ADJOURN**

Wednesday, November

9:00 a.m. Subcommittee Meetings:
Appropriations Subcommittee Drawing Room #2
International Issues Subcommittee Drawing Room #1
Racial Ethnic Populations Subcommittee Mount Vernon C
 Update on Healthy People 2000/2010
 Invited: Deborah Maiese, HHS
Prisons Subcommittee Drawing Room #3
 Overview/Briefing of Prison Site Visit Agenda and
 National Prisons Meeting
 Invited: Todd Summers, ONAP
 10:30 a.m. **Prevention Subcommittee** Mount Vernon C
 Review and Update Subcommittee Workplan

Wednesday, November 18(continuation)

Services Subcommittee

Drawing Room #1

"Future Leadership on Access to Care and Treatment Issues" Presentation

Invited: David Beier, Chief Domestic Policy Advisor to the Vice President, Vice President's Office; Kathy King, Health Care Financing Administration; Marsha Martin, Ph.D., HHS; Steve Schondelmeyer, Ph.D., University of Minnesota; and Todd Summers, Deputy Director, Office of National AIDS Policy, Member of the White House Access to Care and Treatment Group Task Force

Research Subcommittee

Drawing Room #3

Update and Discussion on Microbicide Development Recommendations

12:00 noon

LUNCH (on your own)

2:00 p.m.

Prevention Subcommittee

Mount Vernon C

Services Subcommittee

Drawing Room #1

Subcommittee Discussion of HIV Cost Services and Utilization Study (HCSUS)

Subcommittee Discussion of Transition to Co-Chair Model for Subcommittee and Division of Responsibilities

Review and Update Subcommittee Workplan

Research Subcommittee

Drawing Room #3

Update and Discussion on Microbicide Development Recommendations

Invited: Penelope J. Hitchcock, D.V.M., Chief of Sexually Transmitted Diseases Branch, NIAID, NIH; and Zeda Rosenberg, Ph.D., Senior Health Specialist, Division of AIDS, NIAID, NIH

Review and Update Subcommittee Workplan

4:00 p.m.

Appropriations Subcommittee

Drawing Room #1

International Issues Subcommittee

Drawing Room #3

Subcommittee Discussion Regarding Full Council Presentations

Review and Update Subcommittee Workplan

Racial Ethnic Populations Subcommittee

Subcommittee Discussion Regarding Full Council
Presentations

Wednesday, November 18(continu

Mount Vernon C

6:00 p.m. Review and Update Subcommittee Workplan
ADJOURN

9:00 a.m. Subcommittee Reports
12:00 noon **ADJOURN**

Thursday, November
Mount Vernon A & B

DRAFT

Talking Points
Presidential Advisory Council on HIV/AIDS
November 16, 1998

Sandra L. Thurman

by
ccmail as well

4/2 [

Welcome all to the meeting and say how glad you are to see them.

Thank Scott for his overview of Council activities and priorities.

Scott mentioned several important points that you would also like to address in your remarks, including the overview of the Council's interim activities as well as progress in developing and implementing the Council's Strategic Plan.

Indicate that you would like to focus your comments on several major activities which have occurred since the last meeting, including:

- Congressional Black Caucus Initiative
- The FY 99 budget
- The Elections/Changes in the Leadership of the House of Representatives
- Update on 1996 Youth Report/Presidential Directive
- ONAP meetings
- Upcoming Prison Site Visit
- World AIDS Day
- December Meeting with the President

The agenda is full and offers many areas of challenge.

Very interested to hear more on:

- Surgeon General's update on the Race/Health Initiative
- Update on Needle Exchange
- Ryan White reauthorization
- hear directly from the new head of CDC, Dr. Jeffrey Koplan
- full Council presentation on American Indians, Alaskan Natives and Native Hawaiians (thank Charles Blackwell for his work on this issue)
- Discussion with the Vice President's and HCFA staff on Access to Care and treatment

as well as a host of other very important and timely issues.

Thank Daniel Montoya for all of his work and that of the Council on developing such an ambitious and focused agenda for this meeting and for all the hard work in preparing for this

meeting.

But first, if I may, I would like to introduce ONAP interns Emily Stewart and Kelli Stewart, and thank them for all of their work at the office. They will both be with us until mid-December, and as I have said of previous interns, they are the back bone of the office and really help keep it running.

Also, thank Sarah Howelinski for her work -- she is in class today learning the theory of how government works while we are here making government work. Hopefully the two are related.

Congressional Black Caucus Initiative

Very pleased by the success that the Congressional Black Caucus had in securing an additional \$165 million in AIDS-related funding for minority communities.

(Note: Sandy should be very careful how she refers to this funding since it is somewhat of a sore point for Latinos, Asians and Indians that they do not appear to be the beneficiaries of any of the new money. The concern is how the funds will be disbursed and what funding if any Hispanics, Asian and Indians get out of this additional funding.)

The CBC and all of those who worked to secure this funding, including many on the Advisory Council should be commended for the efforts and hard work.

State that you are pleased to see this money added, but that you clearly understand that it is not enough to solve the problems in minority communities and that more needs to be done.

State that you will work to ensure that the agencies do not view this new \$156 million in funding as all that they have to do to address minority communities.

State your belief that equal access to the \$7.1 billion in Federal AIDS spending is the goal, and that there must not ever be a "set-aside" for minorities if it means that they do not benefit from all the other Federal AIDS programs available.

The goal should be the full integration, or main streaming, of racial/ethnic populations health care needs into the general scheme of Federal programs.

The work of the HHS Eliminating Race/Ethnic Disparities in Health Initiative that Dr. Satcher will discuss on Tuesday morning hopefully will discuss the Department's efforts to ensure that HIV in minority populations are fully addressed by all Federal agencies within HHS as part of their overall efforts.

Cannot understate how important this money will be to the community, not only because it will fund additional programs and efforts within minority communities, but because of the wake up call the community has sent to its leaders that the time has more than passed for them to not be involved in HIV/AIDS. The community's call for a state of emergency was a drastic step that the troops in the trenches, and I have been one in the past, had to say to their leaders -- if you are not willing to lead, then get out of the way and let those of us who are do so.

Congresswoman Waters made a very important point and promise during her speech at the U.S. conference on AIDS in Dallas a few weeks ago.

She committed the Congressional Black Caucus to working with the Congressional Hispanic Caucus, the Asian Caucus and others to push through a similar effort for these populations. While she initially did not mention Native Americans in her remarks, she returned after her speech to specifically mention Native Americans.

Our job is to take her up on her offer of joining with other groups to secure similar funding for other communities of color. I can tell you that Todd and I have already started working the inner halls of the White House to try and do just that. As with everything we work on, it will be a battle, but one that with your support we can win.

Thank again everyone who attended the White House event regarding the announcement.

Denise Stokes gave a wonderful, impassioned account of what it is like to live with HIV on a daily basis. Her remarks struck to the heart of the matter, and I think clearly resonated within the White House. Denise is a credit to herself and the Council and I want to thank her for her courage and leadership.

Thank Debra Frazer Howze for all of her work. She was singled out by Congresswoman Waters by name during the Congresswoman's remarks in Dallas at the US Conference on AIDS.

Say it is obvious that the Council and its members have had great influence on this effort, and considering how this was the Council's number one priority, you all should take heart that your efforts do work.

The FY 99 BUDGET

I won't spend a lot of time on the FY 99 budget, but there are a few points I want to make about your, and our successes in securing nearly ½ billion dollars in new funds for AIDS-related activities while at the same time carrying out the President's promise of a balanced budget.

I believe that there is information about the FY 99 budget in your packet (if not, we will provide you will an overview).

Some areas of particular concern to the Council where wonderful successes were made include:

- An additional \$32 million in prevention funding, a 3.5% increase. Still not enough, but a start in the right direction.
- \$261.4 million in new funding for Ryan White, a 19% increase, with almost 70% of that increase going to ADAP.
- a nearly 10% increase in NIH's AIDS research budget.
- a nearly 19% increase in SAMHSA's budget -- finally.
- and a nearly 10% increase in HOPWA funding.

These are wonderful increases, and the Advisory Council should be commended for their work in helping to secure these funds.

(This needs more on ONAP's role in securing these funds and working with Congress. Should also thank Congress for their support.....)

The Elections/Change in House of Representatives Leadership

Another issue I want to briefly discuss, since I am not sure yet what it means for AIDS issues, is the change in leadership in the House of Representatives, with the Departure of Newt Gingrich and the apparent assumption as Speaker of the House by Congress Robert Livingston of Louisiana.

As many of you know, Congressman Livingston was chair of the very powerful House Appropriations Committee.

For the most part, he has been very supportive of AIDS funding issues, and he helped ensure the major increases we received in FY 99.

With his move to the Speakership, it remains to be seen who will be selected as chair of the Appropriations Committee and what they think about AIDS issues, as well as who will be elected to the other important leadership positions within the House (THIS MAY BE KNOWN BY MONDAY, BUT I DOUBT IT.)

Regardless, our job is to forge a new working relationship with whomever takes over the Appropriations Committee and work with them to ensure that they understand the needs of people with HIV and the importance of prevention and research.

ONAP meetings

Todd, I need help here, I know about the following but do not know enough to write talking points:

recent meeting at ONAP on ASIAN international issues

recent meeting of the WH Access to Care and Treatment Task Force

Interdepartmental Task Force on AIDS did **NOT** meet since the last meeting.

Upcoming Prison Site Visit

Should SLT discuss this or you? You will be discussing this in a subcommittee meeting as well.

Update: 1996 Youth Report / 1997 Presidential Directive on Youth

ONAP staff (Matthew) has been working with HHS to conduct an review of the recommendations contained in the 1996 Youth Report to the President, and to respond to the 1997 Presidential Directive on Access to HIV Information and Services for Youth.

As part of the youth directive, each Department was asked to provide an inventory of programs which had the potential to reach youth with HIV/AIDS information, and to develop new steps to reach youth.

Each Departments responded with the inventory portion of the request, and we now have a fairly good list of what is currently occurring with the Federal government as it relates to HIV .

We have now cross walked this list of programs with each of the 10 recommendations contained in the 1996 Youth Report, to see if there are any gaps. The initial review indicates that we are addressing each of the 10 recommendations at some level, but that of course does not mean that more work can not be done.

In addition, several of the Departments developed new activities that they will implement that responded to the Presidential Directive on increasing access to HIV prevention information and services for youth.

This list was not nearly as expansive as we had hoped, and to put it frankly, for the most part, we were disappointed with their responses. But in all fairness, it is clear from the inventory we developed that we are already doing a heck of a lot of work in this area.

Most Department's will doing the following types of things:

Sending letters to all their grantees asking them to coordinate efforts with local ASO and CBOs'
Asking grantees to put point-of-service displays in public areas of their offices/facilities
Developing specific mailings/newsletters focusing on HIV and youth for distribution to all clients.

I would like to single out the Selective Service Administration for agreeing to include in their mailing to all youth who are required to register for the draft a fact sheet on HIV/AIDS in youth a part of that mailing.

ONAP is still discussing with Housing and Labor the creation of a new program aimed at summer youth.

(Todd: details here based on what you work out)

I must say that the inventory of what we are doing, though, is not an indication of how well we are doing with what we have, or even if we are doing the right things in the right way. That type of assessment in itself could be very useful, and very costly.

As part of the Report, we plan on including an inventory of all current programs which target/reach youth, as well as contact information for each program. This in itself will serve as a wonderful resource for the public, as well as for Federal officials.

Release Date:????

WORLD AIDS DAY

World AIDS Day is December 1.

The theme is "Be a Force for Change," and is focused on youth, 13 - 21.

ONAP staff (Matthew) has been working with each of the Federal Departments to encourage each of them to develop specific World AIDS Day observances.

This year, several things will be happening that are worthy of noting, including:

◆ **President:** Scheduled but not yet confirmed, the President will be meeting with a

small group of youth to discuss youth-specific issues. We have asked for approximately 30 minutes, including a 5 minute photo op. The remaining 25 minutes will allow the youth to bring up their concerns.

- ◆ **Vice-President:** do you want me to call over and ask?
- ◆ **Mrs. Clinton:** do you want me to call over and ask?
- ◆ **Mrs. Gore:** (I sent a note to Miguel Bustos asking for her schedule)
- ◆ **Sandy Thurman:** will she be going to New York? (I do not know the details). Also, will she be attending the event at George Washington University being arranged by Paul Yandura's partner?)

In addition, for the first time, each federal Department will have a message on World AIDS Day either printed on their pay stubs or provided via electronic mail or desk to desk memorandum.

The message will read: "More than 50% of all new HIV infections are in youth under the age of 25. Have you talked with your loved ones about how to prevent HIV infection. Call 1-800-458-5231 to find out how."

In addition, ONAP staff is working with the National AIDS Hotline to have both Dear Abby and Ann Landers run World AIDS Day related columns. (Todd, not hearing back from you or SLT on the draft letter, I went to the Hotline since they have done this in the past.)

We also plan on doing a press release listing out all Departmental activities for World AIDS Day, as has been done in the past.

Finally, as done in the past, the White House will dim the lights at 8:45 p.m. in honor of those who have died of AIDS and are living with HIV.

December 19 Meeting with the President

Is this something SLT should discuss or will it be covered by Scott Hitt?

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