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PRESIDENTIAL

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COUNCIL ON

HIV/AIDS

July 1, 1999

MEMORANDUM FOR KEVIN THURM, DEPUTY SECRETARY, DEPARTMENT OF HEALTH AND HUMAN SERVICES

FROM: R. Scott Hitt, M.D., Chair

RE: "Know Your Status" Campaign and Health Care Worker Guidelines

The Executive Subcommittee looks forward to meeting with you on July 13, 1999 at 10:00 a.m. in Washington, D.C. PACHA had a great meeting in June and I anticipate an equally positive and productive meeting with you.

Council members are more enthusiastic than ever about strengthening the relationship between PACHA and HHS. These meetings present an ideal opportunity for teamwork within the administration in the fight against AIDS.

I know that the Executive Subcommittee is especially interested in receiving a thorough update from you on the following two issues. Although these issues are a priority for this subcommittee, there will be a full agenda for this meeting.

"Know Your Status" Campaign

The Council has continued to stress the necessity of a BOLD initiative in launching this campaign. As a result of our recent meetings and updates it is evident that for this initiative to materialize 3 critical issues must be addressed. These include: 1) providing the leadership necessary to move this process, 2) deciding what resources will be utilized from both CDC and potential public-private partnerships, and 3) establishing a system of accountability between HHS, CDC, ONAP.

At our recent full council meeting (June 7-8) the council was impressed that the CDC had worked to build a week of activities around National Testing Day. However, cross-agency leadership needed to bring a national focus to this campaign is still not evident. To facilitate leadership, communication and coordination amongst HHS, CDC, and ONAP and establish an efficient system of accountability the council has recommended placement of an FTE coordinator (from CDC) at ONAP.

Healthcare Worker Guidelines

Council members discussed the urgency of finalizing the HIV+ Healthcare Worker Guidelines. These guidelines remain critical for healthcare professionals and in the meantime doctors and other healthcare professionals continue to lose their jobs. At our recent full council meeting in June (7-8), Dr. Helene Gayle stated that CDC's review of these guidelines would

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Washington, DC 20503

be complete within a week to 10 days, and the document would then be forwarded to HHS. I am recommending the development of a detailed timeline outlining the finalization process of these guidelines to be discussed during our meeting.

Please let me know if you need additional information on any of these two issues. I can be reached at my office (310) 652-8729 x3339 or you can call Daniel Montoya at (202) 395-1445 and have him arrange a time for us to talk.

Thanks. See you in Washington!

August 6, 1997

PRESIDENTIAL

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COUNCIL ON

HIV/AIDS

The Honorable Donna E. Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue
Washington, D.C. 20201

As members of the President's Advisory Council on HIV/AIDS, we are writing to express our urgent concern regarding certain HIV/AIDS-related issues and to request a meeting with you prior to September 30, 1997, to discuss those issues. Such a meeting should serve to expedite resolution of critical, time sensitive issues which currently impede fulfillment of the President's stated goals for ending this epidemic. In the President's words, "[t]o achieve these objectives, we must all stand shoulder-to-shoulder in our fight."

In keeping with the responsibilities assigned to us by the President, this Council, in consultation with leading medical and public health officials and with community-based AIDS groups, has investigated the federal response to AIDS. Following extensive deliberations, the Council has issued recommendations that represent our judgment regarding how best to realize the President's clear commitments and directives regarding AIDS.

Many of those recommendations have been referred for your response. Disappointingly, those recommendations have been, in large measure, either ignored or insufficiently acted upon by the Department of Health and Human Services. Silence on these issues has become increasingly frustrating and detrimental to the partnership necessary for achieving the President's goals.

As part of our continuing assessment of the Administration's response to AIDS, the Council will issue in December another status report to the President. A meeting to discuss outstanding issues of concern regarding HHS policies is urgently required to complete that task. Particular focus on development and implementation of a comprehensive strategy to accomplish the President's goal of "reducing the number of new infections each and every year until there are none" including addressing substance abuse and its effect on HIV transmission, along with both the availability of and access to treatment, is essential to that process.

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Most pressing among those issues on which response has been inadequate are:

- Timely elimination of restrictions on the use of federal funds for needle exchange and failure to exercise the waiver authority granted by Congress, despite clear scientific evidence of the efficacy of and growing public support for such programs.

- Implementation of the Administration's initiative announced over three months ago, to undertake a 30-day study of expanding Medicaid coverage for early intervention therapy for low income HIV infected individuals who have not yet become legally disabled.

- Prioritization in the FY 1999 Administration budget request of funding for AIDS prevention and housing, along with reprioritization for AIDS care and research. In particular, HHS plans for implementing the recently issued HIV treatment guidelines and the requisite expansion of primary medical care necessary to provide access to the recommended therapies.

- Removal of existing restrictions on the content of CDC-supported HIV prevention materials, with the goal of establishing accuracy and appropriateness for the target audience as the sole criteria for assessing such materials.

- Immediate review and revision of the scientifically discredited CDC guidelines covering HIV infected health care workers.

- The specific plans of appropriate HHS agencies for their substantive involvement in what should be an expedited, high-priority, well-financed, coordinated, government-wide effort -- with private industry partnerships and international collaborations -- to achieve the declared goal of an AIDS vaccine within a decade.

- Provision of sufficient resources, consistent with the President's commitment in reorganizing the Office of National AIDS Policy, for accomplishing the President's goals. Such resources are critical to systematic institutionalization of the President's policy decisions through development of departmental rules, regulations and directives, along with appropriate coordination and monitoring.

While the Council's initial recommendations targeted research, prevention and service related topics, specific recommendations relating to the particular needs of communities of color, women, children and adolescents, young gay men, prisoners and international populations are in continual development.

The Council sincerely desires to assist the President and his Administration in achieving prompt resolution of these critical issues in a manner which maximizes the federal government's ability to effectively respond to the HIV epidemic.

Your positive response at your earliest convenience to this request for a meeting will be greatly appreciated. We are available for a preliminary conference call or other appropriate prerequisites to such a meeting at your convenience. Please contact Council Chairman Scott Hitt to follow up. Thank you for your consideration.

Sincerely,

R. Scott Hitt, M.D.
Chair, on behalf of the members of the
Presidential Advisory Council on HIV and AIDS

PRESIDENTIAL

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COUNCIL ON

HIV/AIDS

December 8, 1998

The Honorable Donna Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue
Washington, D.C. 20201

Dear Secretary Shalala:

In June 1998, the Presidential Advisory Council on HIV/AIDS (Council) adopted a number of priority areas to serve as its focus for the remainder of its term, including advancing the call for a State of Emergency in the African American and Latino communities and ensuring that HIV/AIDS in racial and ethnic populations is adequately addressed. While we were disappointed that an emergency was not declared, we were very pleased that through the work of the Congressional Black Caucus, the community and the Administration, some $156 million in targeted funding will be made available to address "the ongoing and severe health crisis" in minority communities.

During our November meeting, we identified a number of issues, which we believe need to be addressed by the Department in order to implement the intent of the CBC Initiative and the Department's own declaration of a severe and ongoing health crisis. Each issue is addressed below.

CDC' People of Color Initiative

In July 1997, members of the PACHA Executive and Prevention Subcommittees met with Dr. Helene Gayle, Director, Center for HIV/STD/TB Prevention. During that meeting we were excited to hear that the CDC would be undertaking a People of Color Initiative, which we were informed was still in its planning stages. PACHA made it clear that we were in full support of this effort and asked to be kept informed as it progressed. At its most recent meeting in November 1998, the Prevention Subcommittee was informed by Dr. Gayle that there are no plans to develop this Initiative. Rather, she indicated that CDC plans to invite consultants to further assist the CDC in evaluating its efforts to prevent the spread of HIV in communities of color. This strategic change concerns us.

In March 1998, CDC convened a meeting of leading African American HIV/AIDS advocates and providers to discuss the African American component of what was then being called a People of Color Initiative. We believe that this meeting served as the catalyst for the Congressional Black Caucus request that you declare a state of emergency as it relates to HIV/AIDS and African Americans. The CBC's leadership has led to

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unprecedented public support from African American leaders for increased funding and attention to the HIV crisis in African American communities. Because of Congress and the Administration, these communities will have additional resources in FY '99 to continue to expand their capacity to care for people with HIV and prevent the further spread of HIV. PACHA is concerned that the CDC may lack the capacity to continue to support the expanding efforts among African Americans and other people of color. PACHA believes that the CDC must have specific goals and appropriate programmatic activities to ensure that the HIV prevention needs of each racial and ethnic minority population at risk is evaluated continually and consistently and that health department and community-based efforts are monitored appropriately and managed effectively. We recommend that the CDC be requested to report to you on how this new strategy will ensure that it meets these goals as well as the goals of the President's Initiative to Eliminate Racial and Ethnic Disparities in Health Outcomes.

Healthy People 2010

The Council is concerned with the apparent difference in treatment of HIV in the Healthy People 2010 draft objectives. Based on our understanding of the draft objectives, HIV is the only health area in which the goal is to **reduce** racial and ethnic disparities rather than **eliminate** them. The Council is very concerned how this difference will translate into policy and funding decisions, as well as the message it sends. Currently, some objectives indicate that in the year 2010 it will be acceptable Federal policy to have HIV infection rates higher for minorities than for Whites, or that one group of individuals could have a different AIDS case rate than another. Thus, if these objectives were met, the Nation's goals would have been met. While we understand the difference in targets is based on the impact the epidemic is currently having on these populations, the Council believes that the overall goal should be zero new infections (as stated by the President), and zero new AIDS cases. The Council is also concerned about the lack of data and objectives for sub-populations (e.g., Mexicans, Ethiopians, Koreans, Apaches). We already know that programs must be linguistically and culturally appropriate, and we must have the data in order to know where best to target our resources. Finally, the Council is concerned that the development of these objectives appears to have excluded input from both the Presidential Advisory Council on HIV/AIDS and the Office of National AIDS Policy. Given our role, we asks that formal mechanisms be put in place which will allow for ongoing dialogue to occur in a timely manner.

National Minority HIV Plan

At our November meeting, the Council also reviewed the Interim National Minority HIV Plan, which has been developed by the Office of Minority Health (OMH) in conjunction with community advisors and agency representatives. We applaud OMH's efforts to prepare a comprehensive plan to address HIV/AIDS in communities of color, and urge that the final report be released immediately. While the Council believes that the Interim report would benefit from greater specificity on the part of the agencies with respect to their implementation plans, we are most concerned that it be released as soon as possible so that responsible agencies can meet the deadlines established through this planning process.

As you know, a number of the important recommendations included in this report were first made by community members many years ago, but have yet to be implemented by the federal government. In an effort to accurately reflect this history, the Council requests that OMH include in the final draft of the report a preamble, which makes reference to the fact that the report includes both new and outstanding recommendations. The Council would also like to request a progress report by OMH and other agency staff at its March 1999 meeting.

Funding for the Office of Minority Health

The Council would also like to request formally that you do everything in your power to ensure that the $8 million awarded to the OMH through the Congressional Black Caucus Initiative be restored through a technical amendment to the FY 1999 omnibus spending bill. While the increase is included in Congressioal language, it is not included in the accompanying budget charts. This funding is critical to many OMH functions, including implementation and oversight of the National Minority HIV Plan. It would also directly address concerns raised by the CBC regarding OMH's role in addressing HIV in racial and ethnic communities.

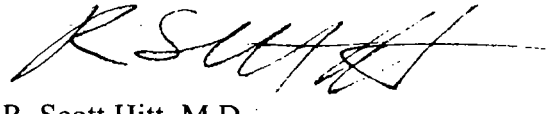
Indian Health Service

The Council is very concerned with the lack of responsiveness on the part of the Indian Health Service (IHS), not only to the recommendations of the Council to update its HIV/AIDS Prevention Program Report and Plan, but also to develop case management oversight guidelines. The unique federal trust responsibility mandates appropriately sensitive and aggressive action by IHS to serve all Native Americans on reservations and in rural and urban environments.

Cancellation of the IHS AIDS drug program has caused confusion and detrimental results to many individual Indian people. IHS should take the initiative to assure that the ADAP program includes the availability of drugs for all Native Americans. It would appear that the federal trust responsibility as embodied in the IHS HIV/AIDS policies and procedures is not being appropriately addressed and fulfilled for treatment, surveillance or prevention. The IHS does not appear to be taking appropriate expeditious initiative to work with other federal agencies or with tribal health programs. Your leadership in moving the IHS to address the needs of Indians with AIDS is sorely needed, not only in the areas identified above, but in all AIDS-related activities.

We appreciate the work that the Department has and continues to do to address HIV/AIDS in the United States and internationally and in the relationship that has been developed between the Administration and the Council. We remain committed to working with you and the Department to develop the best response to HIV/AIDS, and look forward to a timely response to our requests.

Sincerely,



R. Scott Hitt, M.D.
Chair

Presidential Advisory Council on HIV and AIDS

Stephen N. Abel, DDS
Mr. Terje Anderson
Ms. Regina Aragon
Ms. Judith Billings
Mr. Charles Blackwell
Mr. Nicholas Bollman
Jerry Cade, MD
Lynne M. Cooper, D. Min.
Rabbi Joseph Edelheit
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Mr. Bob Hattoy
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Mr. Jeremy Landau
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Mr. Miguel Milanes
Ms. Helen Miramontes
Rev. Altagracia Perez
Michael Rankin, MD
Mr. H. Alexander Robinson
Ms. Debbie Runions
Mr. Sean Sasser
Mr. Benjamin Schatz
Mr. Richard W. Stafford
Ms. Denise Stokes
Rep. Charles Quincy Troupe
Bruce Weniger, MD

PRESIDENTIAL

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COUNCIL ON

HIV/AIDS

March 16, 1998

The Honorable Donna Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue
Washington, D.C. 20201

Dear Secretary Shalala:

As the leading public health official in the country, it is your responsibility to exercise leadership on critical issues affecting the health of the nation. As the Presidential Advisory Council on HIV/AIDS, we urge you to demonstrate that leadership on the issue of needle exchange programs in our common fight against the transmission of HIV.

As you know, the statistics are compelling: injection drug use is directly responsible for half of all new HIV infections in this country annually, and indirectly responsible for the infection of thousands more people who are the sexual partners or children of infected users. HIV transmission related to needle sharing is, to a great extent, responsible for the frightening and disproportionate spread of HIV among African-Americans and Latinos, particularly women.

As you also know, the scientific evidence of the efficacy of needle exchange programs in preventing new infections is equally compelling, and there is no credible evidence that needle exchange programs lead to increased drug use.

We are, therefore, increasingly dismayed by your almost complete silence and continued inaction. This critical health issue demands your leadership, not only inside the government but also on a public level. Needle exchange programs have powerful and vocal opponents. As the nation's leading spokesperson on health you must ensure that science, not unsubstantiated fears, guides this administration's policies.

It is imperative that you state, publicly and unequivocally, what the scientific evidence demonstrates: needle exchange programs meet the two-pronged test laid out in the law. By issuing such a determination you will send an important message to the American people, and will help to change the terms of debate and discussion on this issue.

808 17th Street, N.W., Suite 820

Washington, DC 20006

It is equally imperative that you immediately engage the President on this matter by providing him with a full briefing on the scientific data and stressing the critical role needle exchange programs can play in reaching his stated goal of reducing the number of new HIV infections until there are none. We are hopeful that, presented with such compelling evidence and your strong advocacy, the President will immediately act in the interest of public health and bring federal policy into line with current scientific knowledge.

Lack of political will can no longer justify ignoring the science. Every day that goes by means more needless new infections and more human suffering. We call upon you to make an immediate determination and to allow the local use of federal funds for needle exchange programs as part of a comprehensive HIV prevention program. To do anything less would be an abdication of your responsibilities.

Sincerely yours,

R. Scott Hitt, M.D.
Chair

Presidential Advisory Council on HIV/AIDS Members:

R. Scott Hitt, Chair
Stephen N. Abel, D.D.S.
Terje Anderson
Regina Aragon, M.P.P.
Judith A. Billings, Esq.
Nicholas Bollman
Jerry Cade, M.D.
Rabbi Joseph Edelheit
Robert Fogel, Esq.
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Kathleen Gerus
Phyllis Greenberger, M.S.W.
Nilsa Gutierrez, M.D., M.P.H.
Bob Hattoy
B. Thomas Henderson, Esq.
Michael Isbell, Esq.
Ronald Johnson
Jeremy Landau
Alexandra Mary Levine, M.D.
Steve Lew
Helen M. Miramontes, M.S.N., R.N., F.A.A.N.
Rev. Altagracia Perez
Robert M. Rankin, M.D., M.P.H.
H. Alexander Robinson, Esq.
Debbie Runions
Sean Sasser
Benjamin Schatz, Esq.
Richard W. Stafford
Denise Stokes
Charles Quincy Troupe
Bruce G. Weniger, M.D., M.P.H.

PACHA RESOLUTION ON NEEDLE EXCHANGE PROGRAMS

March 17, 1998

WHEREAS we the members of the Presidential Advisory Council on HIV/AIDS have on several occasions advised the President and Health and Human Services Secretary Donna Shalala that the Administration's current policy on needle exchange programs threatens the public health, and directly contradicts current scientific evidence regarding the efficacy of such programs; and

WHEREAS this Administration has yet to put forward a coherent plan to increase access to substance abuse treatment or to combat the spread of HIV among injection drug users and their partners; and

WHEREAS nearly 50% of all new HIV infections, and 44%, 44%, and 61% of all reported AIDS cases among African-Americans, Latinos, and women, respectively, are related to injection drug use; and

WHEREAS the Congress in 1997 reaffirmed Secretary Shalala's authority to make federal funds available for needle exchange programs, provided that she first determine that needle exchange programs reduce HIV transmission and do not encourage drug use; and

WHEREAS no fewer that six federally funded reports (including a 1997 Consensus Report prepared by the National Institutes of Health) and numerous other scientific studies have concluded that the above two criteria have been met; and

WHEREAS the nation's leading public health groups, including the American Medical Association, the American Public Health Association, the National Academy of Sciences, and the Association of State and Territorial Health Officers support needle exchange programs and the elimination of federal funding restrictions; and

WHEREAS 61% of Americans surveyed believe that decisions regarding the use of federal funds for needle exchange programs should be made by local communities and not the federal government; and

WHEREAS it is essential that the nation's health policies be based on sound, scientific evidence rather that on unsubstantiated fears or politics; and

WHEREAS in light of the disproportionate impact of injection drug-related HIV on communities of color in the United States, the Secretary's continuing inaction undermines the credibility of the Administration's stated goal of reducing racial and ethnic health disparities; therefore

BE IT RESOLVED that, in the interest of the public health, and in our capacity as independent advisors to the Administration, we unanimously express "no confidence" in the Administration's commitment and willingness to achieve the President's stated goal of "reducing the number of new infections annually until there are no new infections"; and

BE IT FURTHER RESOLVED that the Council urges Secretary Shalala to issue an immediate determination declaring the efficacy of needle exchange programs in preventing the spread of HIV while not encouraging the use of illegal drugs.

August 6, 1997

PRESIDENTIAL

ADVISORY

COUNCIL ON

HIV/AIDS

The Honorable Donna E. Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue
Washington, D.C. 20201

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Most pressing among those issues on which response has been inadequate are:

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Sincerely,

R. Scott Hitt, M.D.
Chair, on behalf of the members of the
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Presidential Advisory Council on HIV/AIDS

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