FOIA Number: 2018-0758-F

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Issues - Needle Exchange - PACHA [Presidential Advisory Council on HIV and AIDS]

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PRESIDENTIAL

ADVISORY

COUNCIL ON

HIV/AIDS

September 3, 1997

MEMORANDUM TO ERSKINE BOWLES AND BRUCE REED

FROM: R. Scott Hitt, Chair, on behalf of the Presidential Advisory Council on HIV and AIDS

The Council understands that an AIDS-related amendment will likely be offered when the House considers the Labor/HHS Appropriations bill this week. This amendment will revoke or effectively revoke the authority of the Secretary of HHS to lift the prohibition on using federal funds for needle exchange programs.

We have vigorously urged the President and Secretary Shalala, most recently in letters sent by the Council in late July and early August, respectively (attached) to exercise this authority. In June in a meeting with community groups, Bruce Reed expressed the President's commitment to ensure at minimum that, if challenged, the Secretary's waiver authority be preserved.

We are extremely concerned by this threatened action and hope that it will not deter Secretary Shalala from acting promptly to lift the ban on federal funding for needle exchange. Achieving the President's stated goal of reducing new HIV infections to zero, thereby saving tens of thousand of lives, creates an urgent need for swift action.

Fairly or unfairly, the community will measure the President's commitment to ending the AIDS epidemic by the vigor of Administration opposition to this Congressional challenge. The White House position must be clear and forcefully put forth.

In light of the overwhelming scientific support for the efficacy of needle exchange programs in preventing new HIV infections, the ban on federal funding of needle exchange should be lifted immediately. According to the Centers for Disease Control and Prevention one-third of all reported AIDS cases are directly or indirectly related to injection drug use. Secretary Shalala's own report to Congress makes clear the scientific support for lifting the ban.

It is paramount that the President provide personal leadership by directing that his Administration implement a viable strategy for lifting the ban, ensure that all relevant Administration personnel are on board and committed to implementing that strategy, and ensure that the full weight of White House support for preserving the Secretary's authority is being exerted.

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Washington, DC 20006

Many organizations have expressed support for needle exchange programs and their potential for reducing new HIV infections and saving lives. Some of these are the:

American Bar Association;
American Medical Association;
American Public Health Association;
Association of State and Territorial Health Officials;
National Academy of Sciences;
National Black Caucus of State Legislators; and
United States Conference of Mayors.

In addition, major newspapers across the country have expressed their support. Some of these are:

Chicago Tribune
Los Angeles Times
The New York Times
Washington Post
The Plain Dealer (Cleveland)
The Seattle Times

PRESIDENTIAL
ADVISORY
COUNCIL ON
HIV/AIDS

July 26, 1997

The Honorable William Jefferson Clinton
The White House
Washington, D.C. 20500

Dear Mr. President:

Reauthorization of your Advisory Council on HIV/AIDS and recognition that only 40 months remain in your Presidency offer a valuable opportunity for taking stock of our shared commitment to defeat HIV disease. Securing unprecedented funding for AIDS, establishing the Offices of AIDS Research and National AIDS Policy, convening the White House Conference on HIV/AIDS, developing the first-ever National AIDS Strategy and setting a goal of development within a decade of a vaccine to prevent AIDS have been major milestones in this fight, milestones of which you can be justly proud.

We are concerned, however, about the growing perception that in your second term HIV/AIDS issues are not the high priority that they were during the first term and that certain Administration personnel may not share your personal commitment to these issues.

You clearly articulated in the National AIDS Strategy preamble the six simple, but vital goals necessary to end this epidemic. You have told us publicly and privately that you expect us to give you the truth, unvarnished, as we perceive it. In that spirit, we constantly strive to recognize both the accomplishments and inadequacies resulting from Administration actions and to ensure that perceptions of those actions mirror as closely as possible their realities.

As you stated in the opening words of your national strategy, "the epidemic of HIV and AIDS constitutes a public health crisis of unprecedented proportions." The challenges facing us require maintaining the urgency of the "crisis," while pursuing the permanent systemic changes necessary to deal with HIV/AIDS long after you leave office.

If we are to convert the promise of your words to reality for those affected by HIV disease, much remains to be done during the next 40 months.

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The Council is currently reviewing the progress made toward addressing our earlier recommendations, and expects to complete a report in December that will assess both movement on issues and the performance of key Administration officials. During that evaluation process, several critical issues of concern have been raised:

- The Council had previously urged that HIV prevention and housing programs be added to the Administration's list of "investment priorities" that already covered HIV research and care programs. However, the FY 1998 balanced budget agreement with the Congress, is perceived by many as a step backwards in that it fails to maintain the protected status for any AIDS programs. If, in the future, that decision results in AIDS programs being forced to compete with countless other discretionary programs for sharply diminished funding, accomplishment of your stated goals will be seriously jeopardized.

- Acknowledging the dramatic changes in medical management of HIV disease, HRSA recently issued HIV treatment guidelines that recommend antiviral therapy at much earlier stages of HIV disease. Unfortunately, no strategy has been articulated for funding the requisite dramatic expansion in access to HIV therapies and the primary medical care to facilitate that access. The Administration's FY98 budget, for example, failed to propose any additional spending for AIDS Drug Assistance Programs (ADAP) despite urging from 12 Governors of your strong support for adequate funding and also proposed inadequate funding increases for primary medical care through the Ryan White CARE Act. Presidential leadership will be essential to providing adequate resources for this vital safety-net program.

- In April, Vice President Gore announced a major Administration initiative, ordering a study within 30 days of a Medicaid demonstration project to allow States to cover low-income, non-disabled individuals with HIV. The proposed Medicaid expansion, long sought by the AIDS community, would address a serious deficiency in the Medicaid program that has generally required that adults with HIV infection become fully disabled before becoming eligible for coverage. That approach clearly impedes effective early intervention. Although the Vice President proposed only to study, rather than to implement immediately the proposed Medicaid expansion, his comments, which received widespread media attention, clearly indicated an intention to bring this proposal to fruition. Since that announcement, however, there has been little visible progress in making this proposal a reality. Clear direction to take all necessary action to quickly implement this initiative is essential.

- As an essential component of a strategy to achieve your goal of "reducing the number of new infections each and every year until there are no more new infections," your Council has strongly recommended a number of steps to deal with the role of injection drug use in the spread of HIV, including lifting the ban on federal funding for needle exchange programs. Five months ago, senior officials of the Department of Health and Human Services gave public assurance that the Administration intended to study the ban, with a view toward lifting current funding restrictions. However, a strategy for lifting the ban has not yet been developed. Little, if any, clear progress has been made on this crucial issue, notwithstanding the fact that tens of thousands of Americans become infected each year due to contaminated needles and that the science supporting the efficacy of needle-exchange programs is clear. Other potentially promising prevention strategies also remain mired by inaction on the part of Secretary Shalala and HHS.

- In the past, the Council was able to benefit from staff support at the Office of National AIDS Policy to shepherd Council recommendations through the federal bureaucracy. When announcing the appointment of your new Director of the Office of National AIDS Policy you pledged to provide that office with the resources necessary to accomplish your stated goals. The long-term, complex reality of HIV/AIDS will require the institutionalization of your Administration's policies. Systemic change is crucial. In order to ensure such change, adequate attention must be given to translating White House policy decisions into departmental rules, regulations, and policy directives. Staff within the Executive Office of the President must be charged with initiating and monitoring on a constant basis that effort. Based on our recent experiences, current staffing of the ONAP office is insufficient to accomplish your goal. Additional resource commitments and authority must be provided.

- The Council commends your declaration on May 18, 1997 of the goal to develop an effective AIDS vaccine within a decade. This bold step inspired many around the world. To achieve this goal, additional issues must be addressed: all relevant agencies within the federal government must be substantively involved in the AIDS vaccine effort; mechanisms of collaboration and cooperation should be implemented among these federal agencies; the U.S. Government must establish means to communicate, aid, and collaborate with international efforts for vaccine research, development and utilization; the government should facilitate public-private discussions to encourage cooperation and partnerships among government and industry; and specific sources of new funding for AIDS vaccine development must be identified.

Action on these items is needed immediately not only to continue our long national fight against the disease but to reassure the AIDS community that your Administration still sees HIV/AIDS as the important priority you so clearly made it during your first term. We would like the opportunity to meet soon with you and any appropriate Administration officials to best determine how to advance our common agenda.

Sincerely,

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

Presidential Advisory Council on HIV/AIDS

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

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

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.

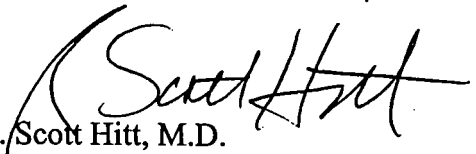
- Provision of sufficient resources, consistent with the President's commitment in reorganizing the Office of National AIDS Policy, for accomplishing the President's goals. Such resources are critical to systematic institutionalization of the President's policy decisions through development of departmental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