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Presidential Advisory Council on HIV/AIDS

13th Meeting

June 7-8, 1999

Radisson Barcelo Hotel

Washington, DC

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Presidential Advisory Council on HIV/AIDS

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Presidential Advisory Council on HIV/AIDS
Full Council Meeting

June 7-8, 1999

Radisson Barcelo Hotel
Washington, DC

MINUTES

Present:

R. Scott Hitt, M.D., Chair
Stephen N. Abel, D.D.S.
Terje Anderson
Regina Aragon
Barbara Aranda-Naranjo, Ph.D.
Judith Billings, J.D.
Charles Blackwell, J.D.
Jerry Cade, M.D.
Lynne M. Cooper
Rabbi Joseph A. Edelheit
Robert Fogel
Debra Fraser-Howze
Kathleen Gerus
Phyllis Greenberger
Nilsa Gutierrez, M.D., M.P.H.
B. Thomas Henderson
Michael T. Isbell, J.D.
Ronald Johnson
Alexandra Mary Levine, M.D.
Steve Lew
Miguel Milanes, M.P.A.
Helen H. Miramontes, R.N.
Michael Rankin, M.D.
H. Alexander Robinson, M.B.A.
Debbie Runions
Sean Sasser
Benjamin Schatz, J.D.
Denise Stokes
Charles Quincy Troupe
Bruce Weniger, M.D.

Present from ONAP:

Sandra Thurman, Director
Todd Summers, Deputy Director
Daniel Montoya, Executive Director, PACHA

Absent:

Nicholas Bollman
Robert Hattoy
Jeremy Landau
Rev. Altagracia Perez

Monday, June 7, 1999
Morning General Council Session

Dr. R. Scott Hitt, Chair, opened the Thirteenth Meeting of the Presidential Advisory Council on HIV/AIDS (PACHA) at 8:30 a.m. He immediately introduced Sandra Thurman, Director of the Office of National AIDS Policy (ONAP), as she had to leave the Council meeting early to attend the White House Conference on Mental Health.

Sandra Thurman, Director, ONAP, and Todd Summers, Deputy Director, ONAP
Update on ONAP Activities

Vaccine Research Center (VRC): Ms. Thurman began by announcing the dedication of the Dale and Betty Bumpers Vaccine Research Center at the National Institutes of Health (NIH) on Wednesday, June 9. She said President Clinton was scheduled to participate in the ceremony, and noted that Dr. Harold Varmus and Dr. Anthony Fauci would give presentations on the state of vaccine research.

Jeffords-Kennedy Bill: Ms. Thurman said the Jeffords-Kennedy bill looked like "a go," and that a vote was pending. The bill ended up at $300 million. She said ONAP was pleased with the efforts of Senators Jeffords and Kennedy, and called the legislation a "nose under the tent of Medicaid expansion."

Medicaid: Ms. Thurman said there had been some progress on the Medicaid front: Maine has submitted and Massachusetts is preparing to submit a waiver, and the Florida and Georgia waivers are still developing. The Department of Health and Human Services (HHS) is providing technical assistance to any State interested in a waiver.

Congressional Black Caucus (CBC): ONAP has been working with the CBC to begin a dialogue on serving communities of color. A round of meetings is scheduled to begin this week.
U.S. Conference of Mayors: During the weekend of June 12-13, ONAP will meet with the U.S. Conference of Mayors to discuss urban issues and HIV/AIDS. Twenty-one AIDS Coordinators will attend the meeting, and Ryan White reauthorization will be among the topics addressed.

Centers for Disease Control and Prevention (CDC): Mr. Summers reported that several Council members participated in a May meeting in Atlanta on the "Know Your Status" campaign, and noted that Dr. Helene Gayle of the CDC would be giving the Council an update during the current Council meeting.

The CDC's prevention planning process is underway to assess the agency's priorities for HIV prevention funding. Mr. Summers said ONAP encouraged CDC, and CDC agreed, to include community group participation in that assessment. A working group of CDC's Community Advisory Board will look at priorities drafted by CDC, and will analyze what the agency is doing with the $640 million allocation. There has been considerable discussion of this issue at CDC, the Office of Management and Budget (OMB), and on Capitol Hill. ONAP's hope is that the process will lead to development of an overarching plan for reducing HIV infections.

Mr. Summers said he did not know the status of the Health Care Worker Guidelines. Regarding the Surveillance Guidelines, he said CDC had hired Larry Gostin of Georgetown University Law School to work on proposed privacy and confidentiality standards. HHS was not satisfied with those standards, so it is currently redrafting and strengthening them. ONAP expects to get a report from HHS on the status of the guidelines soon. ONAP wants to make sure that the confidentiality standards are as strong as the other sections of the draft guidelines.

On the full-time equivalent (FTE) issue, Mr. Summers said CDC is in the process of redoing its budget process to clarify where the agency's money is going and how it is being used, particularly with respect to administrative areas.

African/African American Summit: Ms. Thurman reported that the expanded Presidential Memo on the state of the epidemic in Africa is still being drafted. ONAP is still getting input from members of the delegation to Africa, but she expects the memo will be released shortly.

ONAP staff recently attended the African/African American Summit in Ghana. Reverend Sullivan, a civil rights leader, founded the trade conference 10 years ago, and 5,000 people attended the event this year. This was the first time HIV/AIDS was on the conference agenda. ONAP was excited to participate in the event because ongoing leadership on HIV/AIDS is needed in the religious community and in the African American community. Several Heads of State from Africa participated.

Alexander Robinson, who attended the event, said there was significant discussion of the impact of HIV on economic development in Africa. He said the conference had made an impact on African American leaders, including Jesse Jackson and the Editor of *Essence* magazine, who heard the message about AIDS in Africa and AIDS among African Americans in a new way.

Ms. Thurman said Jesse Jackson gave a 5-minute speech on AIDS in Africa before the African

American delegation departed from Andrews Air Force Base. She said this was significant because it was a high-profile corporate and political group. Secretary of Labor Alexis Herman also included HIV/AIDS in her speeches for the first time, reflecting a multisectoral approach to the issue within Government.

Ms. Thurman said Reverend Sullivan would be arriving in Washington on Tuesday, June 8, to meet with President Clinton for a post-Summit debriefing. Ms. Thurman said she would attend that meeting as well.

State Department, USAID, and Other Agencies: Ms. Thurman said ONAP has been working with Frank Lloyd, Under Secretary for Global Affairs at the Department of State, to reenergize the State Department's response to the epidemic. ONAP hopes for some movement from within the Department now that Mr. Lloyd is in place.
Ms. Thurman said she is pleased that the Departments of Commerce and Labor are showing more leadership on HIV/AIDS; both are participating in the White House Working Group on the expanded Presidential Memo.

She added that the issue of compulsory licensing continues to percolate, and she looks forward to a dialogue with the Council on this very complex issue.

Mr. Summers said the State Department recently released a compendium of U.S. Government programs involved in international AIDS efforts. In conjunction with the release of that document, the Department sent cables to Heads of Missions directing them to engage their counterparts on the issue of HIV/AIDS, with corresponding talking points. The Department is also ratcheting up its efforts in Washington. Mr. Summers recently attended a meeting with 11 or 12 Ambassadors to the United States, Mr. Lloyd, and other representatives from the Department of State and the U.S. Agency for International Development (USAID) to elevate HIV/AIDS as a foreign policy issue.

Ms. Thurman stressed that the Administration's HIV/AIDS work on the international front in no way detracts from its work on the domestic front, but that a global perspective is needed.

Sperm Donation: Mr. Summers said the Food and Drug Administration (FDA) had spoken too soon on sperm donation regulations. The White House and HHS still need to be briefed on the issue. ONAP is expecting a briefing from Kevin Thurm in the next 2 weeks. Whatever the FDA's policy is, it will be closely scrutinized.

302-Bs: Mr. Summers said there is a battle underway on Capitol Hill regarding 302-Bs, which are the allocations given by the Appropriations Committee to each of the subcommittees. The allotments that were handed out corresponded to budget caps established in the past and do not correspond to the income currently flowing into the Government. Mr. Summers said the budget cuts that would be required to maintain the established caps would be "draconian." The Labor-HHS cuts would be approximately $10-12 billion. This could come out of programs like Ryan White, HIV prevention, and research.

Needle Exchange: Ms. Thurman reported that bills have been introduced in both the House and Senate to ban indirect funding of any programs supporting needle exchange. ONAP is organizing a meeting of private funders to facilitate the dissemination of information on needle exchange through private channels. The meeting is planned for fall. Mr. Summers added that HHS is currently drafting a "street-level" guide on the science of needle exchange.

Questions and Comments:
Responding to a question from Regina Aragon, Ms. Thurman said she did not know whether the President would veto any free-standing legislation banning indirect or direct funding of needle exchange programs, but she committed to speaking to the President about it.

Ms. Aragon said final HIV surveillance guidelines issued by CDC later this year should be free of bias. She stated that the Council hopes that ONAP will continue monitoring this issue to ensure that the final draft does not continue to be biased against non-name-based reporting systems and that the presentation of the scientific evidence on the deterrent effects of names reporting be presented fairly.

Robert Fogel asked about the status of the President's understanding of the need for greater funding on global health issues. Ms. Thurman said the President certainly understands the need for greater funding, and that Administration officials at the highest levels are paying attention to it. She said she should have an idea on appropriations for global health in the next week.

Benjamin Schatz asked for an update on the Health Care Worker Guidelines. Dr. Eva Seiler of CDC reported that the guidelines are still at CDC. Dr. Jeffrey Koplan read the draft guidelines and felt more work needed to be done. He was concerned that there were not enough patient protections, so the guidelines are now being "repackaged." Ms. Thurman volunteered to call both Kevin Thurm and Dr. Koplan to inquire about a timetable for release of the guidelines.

Dr. R. Scott Hitt
PACHA Interim Activities

Dr. Hitt reported on three major activities since the last PACHA meeting.

Meeting with Kevin Thurm: The Executive Committee met with Mr. Thurm on April 27, during which Committee members focused on several recurring issues.

Access to Care: Dr. Hitt emphasized to Mr. Thurm that the Council wants to see a "big plan." A one- or two-pager from HHS outlining a policy on access to care would indicate some leadership on the issue.

Know Your Status Campaign: Dr. Hitt said the Committee made it clear that a big, bold initiative is needed, including CDC as well as the White House and ONAP. If CDC continues to lead on this, the campaign may get lost in the bureaucracy. Leadership from above is needed.

Needle Exchange: Dr. Hitt emphasized that new, updated science needs to be disseminated to health experts and legislators across the country. He noted that the opposition has been active in getting its message out, whereas HHS has been silent. A more public role on the part of HHS would have an impact.

Surveillance Guidance: The language has not been finalized yet. The Executive Committee is encouraging HHS to state that unique identifiers are as good as names reporting. From the Council's viewpoint, either one would be satisfactory. This is currently a hot issue in California, where a names reporting bill was recently scuttled, and a unique identifiers bill is pending.

Office of Minority Health (OMH): The Committee urged the Administration to do whatever it can to ensure that the $8 million in OMH funding that was left out of the FY 1999 appropriations bill be restored so that the planned programming can begin.

Health Care Worker Guidelines: Mr. Thurm did not know the status of these.

HHS Regional Meetings: These ended in early June. The Council wants a report on any action taken as a result of these meetings. Mr. Thurm said HHS wants to revamp how they look at AIDS within the Department.

Overall, Dr. Hitt said the meeting with Mr. Thurm was "hard-edged." The Executive Committee conveyed the feeling that there is a lack of leadership at HHS. Issues are not moving. The next PACHA Executive Committee meeting with Mr. Thurm is scheduled for July 13. HHS Secretary Donna Shalala has committed to attend the October Council meeting.

Mr. Summers emphasized that the meeting with Mr. Thurm did have an impact. Following the meeting, Mr. Thurm expressed some frustration to several HHS colleagues that the issues identified by the Council were not moving fast enough.

Dr. Hitt also said he met with the National Organizations Responding to AIDS (NORA) Executive Committee to discuss coordinating timing and strategies on many of the same issues. NORA is focusing on Ryan White reauthorization. Dr. Hitt asked NORA to keep the Council informed on their activities regarding Ryan White.

Letter on Omnibus Appropriations Bill: The Council sent a letter to the President discussing the potential negative impact of the bill on publicly funded HIV/AIDS research.

Letter on the Early Treatment of HIV Act of 1999: The Council also sent a letter asking the President to support the intent of this legislation.

Questions and Comments:
Mr. Summers noted that Dr. Paul Gaist would be starting June 14 as the NIH agency representative at ONAP and would be acting in this role for the next 6 months.

Mr. Summers and Daniel Montoya noted that Dr. Gary Nabel of the NIH VRC wasn't able to attend the current Council meeting due to planning for the VRC dedication, but is interested in attending the October meeting. Dr. Hitt directed Mr. Montoya to set up conference call times to meet with Dr. Nabel.

Dr. Hitt stressed that Council members need to be educated on the compulsory licensing issue, which the International Subcommittee is taking up in its meeting. He said it is important that members not let a few individuals on the Council sway their opinion on the issue, because it is so complex. He added that the Council needs to address it, though it has not been a priority issue to date.

Dr. Hitt said the Council should also consider whether it wants to issue a progress report this fall. He would like input from subcommittee chairs on what such a report should look like, whom it should address, and what message it should convey.

Mr. Anderson asked Mr. Summers if Ms. Thurman could present a statement from the Council on global health appropriations during her meeting with the President and Reverend Sullivan on June 8. Mr. Summers responded that this would violate White House protocol, but that perhaps Ms. Thurman could mention the Council's position.

Afternoon General Council Session
Access to Care Panel Presentation

Dr. Hitt introduced the panel of three Government representatives. Ms. Aragon and Thomas Henderson served as co-facilitators of the panel. Ms. Aragon, representing the Services Subcommittee, began by providing some background on the issue of access to care. She noted that 2 years ago, HHS issued national Guidelines for the Treatment of HIV Disease. These guidelines were hailed by AIDS advocates as a much-needed national standard of care. Access to care is one of the Council's six priorities, and Council members have discussed the issue with the President and with Mr. Thurm on many occasions. The Services Subcommittee has identified a number of key issues related to access to care.

1. *The critical role of supportive services.* Addressing medical care is not enough. Supportive services that facilitate access to care must also be considered.

2. *Appropriations.* Congressional spending caps threaten access to care.

3. *Disparate outcomes across racial and ethnic groups.* HIV-related health outcomes continue to vary by race and ethnicity. Eliminating these disparities must remain a priority for the Council and the Administration.

4. *Medicaid.* The Subcommittee has looked at eligibility criteria. The requirement that someone must be very sick and disabled before qualifying for Medicaid directly contradicts the treatment guidelines, which encourage early access to care. On Medicaid reform, the Jeffords-Kennedy bill includes demonstration projects that could help address access to care, and the Pelosi-Torricelli legislation would allow States to expand Medicaid.

Ms. Aragon said the purpose of the panel discussion was to address an overarching plan to ensure access to the Public Health Service standard of care. What is the baseline for ensuring access to care? What is the plan to reach populations that do not currently have access to care?

Daniel Mendelson, Office of Management and Budget

Mr. Mendelson began his presentation by describing several concerns he has as the congressional appropriations process moves forward. Regarding the 302-B allocations, he noted that the level of funding in the current House Labor-HHS bill is down about 18 percent from last year, while the funding level in the Senate appropriations bill is down about 13 percent from last year. The 18 percent decrease on the House side would translate into a cut in Ryan White funding of about $254 million. HHS has calculated that this would result in denial of services to 69,000 people. Mr. Mendelson called this a "crisis situation," and encouraged the Council to get the message out to the American people.

CDC's reduction is about $118 million for HIV prevention. Mr. Mendelson said there is a problem within CDC, part of which is perception. The "perception" problem is that some of the money that should be going into HIV prevention accounts can't be found. What happens is that there are some line items within CDC where it is very clear that the money is going into HIV prevention, and there are other line items where an allocation methodology is applied. In the latter case, some fraction of the activities of local public health officials is attributable to HIV prevention.

The CDC has initiated a process to assess this. Mr. Mendelson encouraged the Council to let CDC know that this is a priority. He said the Council needs to make sure that CDC programs have the same political cachet as Ryan White programs. Representatives Coburn, Bliley, and Armey have sent a letter to the General Accounting Office (GAO) requesting a full audit of Federal HIV/AIDS programs. This could appear as an appropriations rider and could compromise funding streams and public perceptions of how money is being spent.

Mr. Mendelson mentioned a second potential appropriations rider issue regarding needle exchange. This year's rider would take the position that funds are fungible, prohibiting any recipient of Federal funding from running a needle exchange program. It would deny money to virtually all needle exchange programs currently operating. OMB will oppose this effort, using three arguments. The first is a States' rights position, e.g., telling States how to spend their money is wrong. The Administration will try to get States to oppose the rider. Second, OMB

will point out that the rider would result in a degradation of services. CDC will identify which services will be disrupted. Finally, OMB will emphasize that a broader ban is directly at odds with the scientific evidence.

Regarding the Jeffords-Kennedy bill, Mr. Mendelson said OMB is pleased that the demonstration projects will remain intact. It is critical that the bill be brought to the Senate floor. The demonstration projects will be flexible enough to accommodate waivers for States like Maine.

Eric Goosby, M.D., Health Resources and Services Administration

Dr. Goosby stated that bringing HIV-positive populations without access to care into a continuum of care has been a leading priority for HHS over the last 2 years and will continue to be a priority over the next 3 years. The Health Resources and Services Administration (HRSA) and CDC are the lead agencies in this effort. HRSA has taken on a motto of "100 percent access and zero percent disparity." There is an ongoing effort to look at the linkages between existing lines of treatment—such as STD clinics, family planning clinics, community health centers, and migrant farmworker health clinics—as reservoirs for patients who need to be identified and brought into the AIDS care delivery system.

HRSA is working with the Health Care Financing Administration (HCFA) to develop innovative relationships with States to embrace people without sources of payment. The data coming out of the recent Chicago and Geneva meetings, and from Johns Hopkins University, indicate that this will be a cost-effective approach in the long run.

Dr. Goosby added that HRSA is trying to delineate the factors that contribute to the disparities in longevity, entry into care, development of opportunistic infections, stage of care upon entry into the medical delivery system, and mortality data among minority populations in the United States.

Mike Hash
Health Care Financing Administration

Mr. Hash said HCFA's strategic plan for AIDS has focused on three areas: coordination of services, access to quality care services, and access to care itself.

With respect to coordination of services, HCFA has established a working group with HRSA to address ways to maximize coordination between the provision of funds through the Ryan White Act and through Medicaid and Medicare. Last November, HCFA sent a letter to State Medicaid directors urging them to make coordination of service delivery programs a high priority. Accompanying the letter were two publications: one addressing coordination between Medicaid and Title II of the Ryan White Act, and one addressing coordination between State AIDS **[Eps?]** and Medicaid.

In addition, a survey of State Medicaid Directors is being conducted by the AIDS Treatment Network with support from the Henry Kaiser Family Foundation. The survey addresses State Medicaid coverage and eligibility policies as they relate to persons with HIV, e.g., prescription drug coverage, viral load testing, and new models of service delivery. All but four States have completed the survey to date. HCFA is in the process of analyzing the results.

On quality of care, HCFA is taking steps to maximize adherence to standards of care. A working group at HHS is looking at ways to operationalize the NIH Treatment Guidelines within Federal and State health care delivery programs. The group has taken steps to disseminate the guidelines: the adult guidelines were published in the *Annals of Medicine*, and the pediatric guidelines were

published in the *Morbidity and Mortality Weekly Report*. Both sets of guidelines were also sent out with the State Medicaid Director letter.

Last September, HCFA published a notice of proposed rulemaking implementing certain provisions of the Balanced Budget Act of 1997 with respect to Medicaid and managed care. In that regulation, HCFA solicited comments on the best strategy for ensuring the highest standards for private managed care plans that wish to contract with States to provide services to Medicaid-eligible persons.

HCFA is also participating in a maternal and child health program with State public health departments to develop an appropriate initiative to inform HIV-positive pregnant women and new mothers of infants at risk for HIV of the significance of starting therapy early.

Regarding access to care, HCFA, OMB, and HHS have been working with Maine to flesh out a proposal for an 1115 waiver. The Maine proposal was submitted last November, and Federal meetings with representatives from Maine are continuing. Outside of 1115 waivers, 16 States

now have specially targeted home- and community-based service waivers.

Questions and Comments:

Mr. Henderson asked the panel to comment on Federal development of a broad plan to ensure 100 percent access to quality care across populations. How do the pieces fit together? What is the time frame?

Dr. Goosby acknowledged the difficulty in reaching populations that are becoming increasingly disenfranchised from the mainstream delivery system. But he said HRSA is looking at a 3-year time frame in which the agency would start to see decreasing numbers of people out of care, decreasing numbers of seroconversions, etc. The idea is to create across three agencies — HRSA, CDC, and the Substance Abuse and Mental Health Services Administration (SAMHSA) — an expectation of service integration and program coordination, combining treatment and prevention services. He said HRSA needs to start asking grantees to view their role as "nets of care," so that cooperative relationships are part of the Federal expectation. This would be implemented in the form of guidance expectation and technical assistance delivered by the Federal Government.

Dr. Goosby said there has been an acceptance of this vision at the leadership level in all three agencies, but there are some "big holes" in the reimbursement arena as well as a lack of infrastructure. Some rural and urban areas may prove problematic. This year, there will be three urban demonstration projects coordinated by CDC to integrate services across funding lines. These demonstrations should serve as models. There is also an effort underway to integrate across HIV, STD, and TB programs at the local level. This initiative will begin in 20 cities in FY 1999.

Mr. Henderson asked Dr. Goosby to quantify the universe of those without access to care. Dr. Goosby said HRSA believes there are about 300,000 HIV-positive persons out of care and uninsured. These individuals live predominantly in urban settings, and more than 50 percent are members of minority groups. Pockets in the Native American community, and in San Juan and the Virgin Islands, also pose a challenge in terms of access to care.

Mr. Mendelson noted that it is extremely difficult to redirect streams of Federal funding, and trying to do so may threaten one's base of support. He also said the Government's inability to address access to care for HIV-positive persons has resulted from the fragmentation of the public health delivery system. The Administration did try to address this in a $1 billion, 5-year

initiative in this year's budget. Mr. Mendelson told the Council that OMB is very open to making changes in the appropriations process and in the President's budget request next year.

Terje Anderson commented that he would like to see concrete numbers put forward as part of a broad plan on access to care. Dr. Goosby agreed that high-risk populations in each city need to be concretely identified, along with their geographical locations and behavioral patterns. Once these numbers are derived, the ways in which prevention services interface with each population must be addressed. He said HRSA has attempted to move the dialogue in that direction, but it has been difficult. The Federal Government is used to thinking in terms of States and cities, not specific populations.

Mr. Henderson stressed that the 300,000 figure needs to be broken down into segments for which strategies to improve access can be implemented.

Dr. Stephen Abel asked Dr. Goosby what methodologies are available through Ryan White to carry out quality assessments, and if such assessments could be mandated into HRSA's programs. Dr. Goosby responded that few methodologies are available. HRSA understands this need and in the last year has shifted its focus for technical assistance onto quality assurance. The agency recently hired Dr. Michael Johnson to develop a quality assurance capability at HRSA that will encompass technical assistance and the AIDS educational training centers. The agency has reorganized its resources to make quality assurance a real priority.

Dr. Goosby also noted that the tight administrative caps in Ryan White make it difficult to place a large expectation on grantees to develop a quality assurance capability. The HCSUS study pointed out these areas of deficiency.

Mr. Mendelson said it is very difficult to keep outcomes measures current, particularly when treatment is evolving as rapidly as it is for HIV/AIDS. Therefore, he is concerned about tying specific outcomes measures to money. It could have unanticipated consequences.

Mr. Hash added that HCFA is working to find ways to hold integrated health care plans accountable for meeting appropriate standards and to demonstrate performance improvement annually.

Ms. Stokes questioned the Government's ability to go beyond outcomes measures to define quality care, assessing factors such as patients' ability to get appointments with their local Ryan

White-funded physician. Dr. Goosby said it would be difficult to get to that level of intimacy with a grantee and suggested that the appropriate Federal role in a situation where inappropriate care is being provided with good outcomes measures should be discussed.

Returning to the issue of Ryan White administrative caps, Ms. Aragon said it is important for HRSA to be able to keep and use the 1-percent technical assistance and evaluation shave available through the Ryan White Care Act, rather than have these funds distributed to other HHS programs. This would allow HRSA to provide more robust technical assistance and evaluation.

Mr. Summers added that perhaps funds could be obtained through channels that are not designated as HIV- or AIDS-specific, such as the Minority Health Professions Act.

Mr. Robinson emphasized the need for Federal agencies to specifically address the lack of infrastructure in racial and ethnic minority communities. Where the infrastructure exists, HIV/AIDS dollars either aren't available or haven't been distributed.

Rabbi Joseph Edelheit asked the panel if the estimated 69,000-person drop in the number of HIV-positive individuals served as a result of the House budget cut is included in the 300,000 figure of HIV individuals currently out of care. The panel agreed that the 69,000 figure is probably not included in the 300,000 total.

Rabbi Edelheit also asked Dr. Goosby to explain HRSA's and CDC's timidity on the "Know Your Status" campaign in light of HRSA's goal to identify all seropositive individuals. Dr. Goosby responded that the two efforts are linked and that both agencies hope they will complement each other. Mr. Robinson added that it is critical to normalize the idea of being tested.

Dr. Hitt said he thinks the 300,000 out of care number is an underestimate, considering that there are about 900,000 HIV-positive individuals in the United States, and it is estimated that a third don't know their status.

Mr. Fogel asked the panel to explain why various HIV/AIDS initiatives are moving so slowly through the Federal process. Referring specifically to 1115 waivers, Mr. Hash noted that HCFA takes care to consider what kinds of precedents it might be setting and what kinds of unintended consequences might occur as a result of the agency's decisions on waivers. The agency must

contend with a variety of statutory restrictions, and budgetary and programmatic concerns, to preserve Medicaid as an entitlement program.

Mr. Summers noted that, in the case of 1115 waivers, and specifically the Maine waiver, the process is a dialogue with the State involved, so delays are incurred on the part of both Federal and State negotiators.

Lynne Cooper commented that the lack of supportive services is often the biggest obstacle to access to care.

Mr. Anderson told the panel that a sense of urgency needs to be reinstilled in the Administration regarding making lifesaving treatments available to HIV-positive individuals.

Barbara Aranda-Naranjo stressed the need for the Administration to expand access to care for the 300,000 individuals living with HIV who are out of care. She noted that these individuals do not have the resources to come to Washington to advocate for themselves, so it is important for the Council to represent their interests.

Bringing the discussion to conclusion, Ms. Aragon said one of the most important things mentioned by the panel was the figure of 300,000 out of care individuals. She said this figure should serve as a starting point to establish a plan to broaden access to care, and requested that panel members convey the Council's request for a comprehensive plan to Secretary Shalala.

Mr. Mendelson noted that many people in the Administration had worked hard to push the Jeffords-Kennedy bill through, and that the legislation, if passed, would address some of the Council's fundamental concerns.
Dr. Hitt summed up by saying that leadership and coordination are clearly lacking in each of the agencies represented on the panel. He reiterated the need for a one-page memo from each agency outlining the obstacles to improving access to care and setting forth an overall plan and a proactive approach.

Tuesday, June 8
Afternoon General Council Session

Public Comment
Wayne Turner, ACT-UP, Washington, DC

Mr. Turner discussed AIDS accountability and the need to strengthen community oversight of Federal AIDS funding. He told the Council about a trial underway in Puerto Rico, where eight people have been charged with embezzling $2.2 million in Federal AIDS funds. Six of the eight have pleaded guilty, and the Governor of Puerto Rico is implicated in receiving $250,000 in AIDS funds for his 1992 political campaign. Activists are holding daily vigils outside the courthouse to bring attention to the fact that when AIDS money is stolen, people die.

Mr. Turner said the minority leader of the Puerto Rico State Legislature wrote a letter to Secretary Shalala in 1993 outlining irregularities and conflict of interest violations concerning AIDS funds. He posed the question: If HRSA had carried out its oversight function in 1993, how many people might still be alive?

He said the situation in Puerto Rico is not an isolated one. Council members need to examine ways to strengthen oversight so that this does not keep happening. ACT-UP, the AIDS Accountability Project, and others have called for a GAO performance audit on AIDS funding. He noted that it was Republican Representatives Coburn, Bliley, and Armey who wrote a letter to GAO requesting an audit.

Mr. Turner offered two proposals: The GAO audit must be carried out, and conflict of interest rules must be enforced. In Washington, DC, for example, only 4 of 60 planning council members are not drawing salaries and are not board members of organizations receiving Federal AIDS money. The planning councils are built-in structures for community oversight, and membership requirements need to be adjusted to ensure there is no conflict of interest.

Comments:
Mr. Robinson said the Council had been engaged with local agencies to support them in their oversight activities, but the Council could play a greater role in this area.

Mr. Anderson noted that the HRSA AIDS Advisory Committee met in May to draft a series of recommendations regarding the reauthorization of the Ryan White Act. One of the recommendations stated that at least 51 percent of the membership of any planning body should be free of any conflict of interest as defined in the law.

Debra Fraser-Howze urged the Council to be cautious about supporting the performance audit. She noted that, historically, every time a large amount of funding is directed to communities of

color, a call for an audit follows. She said the AIDS community should wait to see how things play out in Puerto Rico before laying blame. Dr. Aranda-Naranjo and Helen Miramontes also questioned the intent of those behind the audit request.

Charles Troupe stressed that the issue of misappropriation of funds is indeed a partisan one, and that the AIDS community should not look to Republicans for sympathy and support.

Subcommittee Reports

Research Subcommittee

Dr. Levine first reminded Mr. Montoya to schedule a conference call with Chris Collins. She noted that Representative Pelosi has sponsored a bill, H.R. 1274, to give a 30 percent tax credit to corporations or individuals doing vaccine research for any disease that kills more than one million people worldwide per year. The credit would not apply to those doing research under any Government grant or contract. The subcommittee will seek more information on the bill and will report back to the Council in October. The subcommittee expects to speak to Dr. Nabel via conference call regarding the vaccine research effort at NIH.

She said Michael Isbell reported on recent activities of the International AIDS Vaccine Initiative (IAVI). IAVI is focused on moving quickly, trying innovative approaches, and working with underdeveloped nations. The organization is developing international partnerships. One partnership, linking Oxford University in England with the University of Nairobi in Kenya, is focusing on a DNA viral approach to a vaccine. This initiative is expected to move into clinical trials later this year.

A second partnership is using Venezuelan equine encephalitis as a vector for testing a vaccine. This initiative joins Venezuela and South Africa and is expected to move into clinical trials in early 2000.

IAVI also received a $25 million donation from Bill Gates, which will be distributed in sums of $5 million a year. The subcommittee anticipates a conference call with IAVI over the summer to offer the Council's assistance.

Dr. Judith Auerbach of the Office of AIDS Research at NIH also spoke to the subcommittee about behavioral interventions. The NIH budget for behavioral and social science research increased by 21 percent this year; the only other increase that was comparable was for vaccines,

which rose by 31 percent. The money being spent this year for behavioral interventions research is $213 million, while the vaccine funding level is $148 million — a figure that is still very low.

NIH is looking at settings as they relate to minority populations, gender, and drug use, and is doing very applied, focused, intervention-based research. The subcommittee asked Dr. Auerbach for a complete listing of research projects in this area. Dr. Levine noted that Dr. Neal Nathanson

should be commended for moving quickly in this direction. NIH's funding priorities in this area are on primary prevention, secondary prevention, and methods.

The subcommittee expressed a concern that there is a disconnect between NIH and CDC that impedes the translation of research into actual interventions. Dr. Helene Gayle of CDC agreed that this is a problem and that an administrative mechanism is needed. The subcommittee also stressed that all of the players need to be communicating all of the time. Dr. Gayle said she would take these concerns back to CDC. If nothing happens by the next Council meeting, the subcommittee will make a formal recommendation regarding these issues.

The subcommittee scheduled three conference calls for July 21, August 18, and September 15 or 16, all at 10:00 a.m. One call will be with Dr. Nabel, one will be with IAVI, and one will be related to the Pelosi bill.

Dr. Hitt asked if there had been any opposition to the Pelosi bill. None of the Council members had heard of any opposition. He also asked about coordination on the vaccine effort. Dr. Levine said the Council should wait to be briefed by Dr. Nabel at the next meeting.

Ms. Miramontes noted that the AIDS Vaccine Advocacy Coalition (AVAC) had just released a report called "Eight Years and Counting" on the vaccine effort. She called AVAC and requested enough copies for each Council member.

Prevention Subcommittee

Mr. Robinson reported that the subcommittee discussed CDC's efforts related to prevention. First, a CDC Advisory Committee working group is carrying out an inventory of CDC's AIDS-specific programs and examining their priorities. Dr. Gayle said this process should be completed by July or August, and a report will be issued. The subcommittee expressed some skepticism about the value of this process, but decided there are some benefits, such as broader access to information. Dr. Gayle said she would update the subcommittee once the process is

completed.

Since the process is an internal one, the subcommittee is concerned about the objectivity of any resulting recommendations. Mr. Robinson noted that the GAO audit will occur simultaneously, and this has sparked a commitment among some to implement significant changes in CDC's approach.

Second, the subcommittee received an update on the "Know Your Status" campaign. Members were impressed that the CDC has worked to build a week of activities around National Testing Day. However, the cross-agency leadership needed to bring a national focus to this campaign is not evident. Therefore, the subcommittee has committed to biweekly meetings with representatives from HHS, CDC, and ONAP to gauge their progress on the campaign, and to coordinate access to and use of resources and contacts. The subcommittee also suggested that a CDC coordinator for the campaign be placed at ONAP.

After some discussion, it was decided that Dr. Hitt would send a memo to Mr. Thurm prior to the July 13 meeting recommending placement of an FTE coordinator by CDC at ONAP. Ms. Thurman said Dr. Gayle had been trying to recruit someone to take the position but had not been successful. Dr. Hitt said he would call Dr. Gayle to reinforce the message that the FTE is a priority for the Council.

At Dr. Hitt's suggestion, it was decided that Mr. Anderson would send out a general broadcast fax or e-mail to all Council members following each biweekly meeting on the "Know Your Status" campaign to update everyone on campaign activities.

The subcommittee also discussed the Health Care Worker Guidelines. Dr. Gayle said that CDC's review of the guidelines should be complete within a week to 10 days, and the document would then be forwarded to HHS.
Dr. Hitt suggested including a request for a timeline on the guidelines in the memo to Mr. Thurm.

Mr. Montoya reminded all subcommittee chairs that they should submit in writing any items to be included in the memo to Mr. Thurm prior to the July 13 meeting.

Finally, Mr. Robinson mentioned that the update on the 1996 youth report **[is this from CDC ?]** is underway, and is expected to be released by World AIDS Day. The subcommittee also

recommended that Dr. Koplan be invited to the October meeting when Secretary Shalala is present.

Dr. Hitt suggested that the Council's Executive Committee try to schedule a preliminary meeting with the Secretary and Mr. Thurm before the October meeting.

Racial and Ethnic Populations Subcommittee

Dr. Nilsa Gutierrez said the subcommittee decided to organize a presentation to the full Council on the character of the epidemic in Latino communities, to be given at the October meeting. An outline of the presentation was distributed to each Council member. The presentation will address six areas: a general overview of Latino subpopulations; the health status of Latino populations; HIV infection trends and problems of underreporting; the particularities of the health care infrastructure in Latino populations; the impact of substance abuse and use in the spread of HIV infection; and the case of the Virgin Islands, where the Government is facing bankruptcy and a rapid degradation of services is occurring.

The presentation will take 90 minutes. How the epidemic has affected the gay Latino community, women, and inmates will also be addressed.

Dr. Hitt said the presentation was a good idea, but that the Executive Committee needs to rethink logistics and scheduling for the October meeting in order to fit everything in.
Ms. Aragon suggested that Latino community leaders be invited to the October meeting for the presentation and a followup meeting.

Dr. Gutierrez said the subcommittee had also decided to begin to include the Latino perspectives of non-governmental organizations, immigration coalitions, and public interest attorneys in subcommittee meetings. Aspects of the epidemic in Mexico and Puerto Rico will also be discussed in future subcommittee meetings.

Mr. Montoya said he needed to clear logistics for the Latino presentation with the subcommittee.

Steve Lew added that the subcommittee would also like to schedule a discussion of Asian and Pacific Islander (API) populations at a future Council meeting. Charles Blackwell noted that the President just signed an executive order on API health care issues, and that the issue might be appropriate for the December Council meeting. He added that the Council may need to revisit a discussion on Native American populations, and that an interim meeting of the subcommittee

might be needed.

Mr. Montoya said the Council should push for the new Presidential Committee on APIs to schedule a presentation on HIV/AIDS to highlight not just health issues related to HIV, but education and labor issues as well.

International Subcommittee

Mr. Anderson reported on several presentations before the subcommittee on the compulsory licensing issue, including those from the Pharmaceutical Research and Manufacturers of America (PhRMA), Medecins Sans Frontieres, the World Bank, the Joint United Nations Programme on HIV/AIDS (UNAIDS), the Health Gap Coalition, and consumer advocates.

Mr. Anderson said the ways in which U.S. copyright, patent, and trade policies affect compulsory licensing are not easily understood, and the subcommittee is struggling to understand all of the issue's implications. The subcommittee would like to focus on two tasks: (1) a further examination of current and future U.S. policy on compulsory licensing, which would involve hearing from U.S. Government agencies, and (2) a fact-finding of perspectives from the developing world. A conference call or interim subcommittee meeting with several U.S. Government representatives is tentatively planned for this summer.

Mr. Anderson also emphasized that the U.S. Government's response to HIV/AIDS on a global scale needs to be considered as part of the discussion on compulsory licensing.

Mr. Anderson said he would distribute copies of the written statements submitted by those presenting before the subcommittee. Mr. Montoya indicated his staff members would be writing a summary of the subcommittee's session on compulsory licensing.

Mr. Anderson said the subcommittee should be able to make a presentation on compulsory licensing to the full Council by the December meeting. Mr. Montoya said his office would be sending out a lot of information on compulsory licensing, and stressed that each Council member has a responsibility to read the information because the issue is so complex.

Mr. Anderson noted that the Council needs to determine what parallels exist with regard to compulsory licensing for other drugs and diseases.

Dr. Hitt mentioned that *The Village Voice* had published an article about Vice President Gore's

position on compulsory licensing in South Africa. Ms. Thurman said her office had drafted talking points in response to the article. She said the Vice President had not sided with the pharmaceutical industry per se, but had advocated strong patent protection and finding a balance between providing incentives for drug development and protecting profits.

Mr. Anderson clarified that South Africa is not currently using compulsory licensing, but a law is on the books that would allow it. There is concern in the U.S. trade community about the potential impact of this law.

Ms. Thurman noted that there have been times when the United States and other countries have used compulsory licensing, so the Administration is gathering information and determining what precedent has been set.

Mr. Troupe questioned whether pharmaceutical companies are seeking excessive profits in the developing world. Ms. Greenberger commented that pricing, compliance, and patent issues make compulsory licensing a complicated issue — it's not just about profits.

Dr. Bruce Weniger said he was surprised at the U.S. Government's aggressiveness in pursuing punitive action (e.g., withdrawing tariff preferences) against South Africa before any licensing had actually occurred.

Dr. Hitt noted that generic AZT is available in Canada and costs about 40 percent less than what it costs in the United States. Mr. Anderson noted that this was a parallel trade issue, not a compulsory licensing issue.

Dr. Hitt requested that someone on the International Subcommittee draft an executive summary on compulsory licensing as the discussion progresses.

Mr. Anderson said most national organizations are really struggling to develop a position on compulsory licensing. UNAIDS is currently working on a position statement, and it would be instructive to look at that statement when it is released.

Ms. Thurman said she recently met with Peter Piot of UNAIDS and representatives of the Vice President's office, the Department of Commerce, and the U.S. Trade Representative's office to discuss the Administration's policy on compulsory licensing. The group drafted an initial set of talking points, but a complete policy statement is still being debated.

Appropriations Subcommittee

Ms. Aragon reported that the subcommittee discussed the FY 2000 appropriations process and the budget caps issue that Mr. Mendelson addressed in his presentation to the full Council. She noted that this is a serious situation for both the Labor-HHS bill and the VA-HUD bill. She said House Speaker Dennis Hastert has been talking about transferring some Department of Defense money to HHS. She urged Council members not to be deceived by this move, as the amount of the transfer would be insignificant in comparison to the cuts taken to meet the budget caps. This move could end up undermining the AIDS community's advocacy efforts. It is important that advocates make AIDS a "squeaky wheel" and convey the message that the budget caps are not acceptable.

The subcommittee would like an update from the Administration in October on how the $156 million from the CBC is being spent. The CBC is leading an effort to add $180 million in new funding for HIV/AIDS to the FY 2000 appropriations bill. This funding request would probably include Latinos and other communities of color in addition to the African American community.

Ms. Aragon asked that the Appropriations Subcommittee, the Racial and Ethnic Populations Subcommittee, and the International Subcommittee meetings not overlap during the October Council meeting.

Mr. Troupe suggested that money lost through the budget caps might be replaced through funding from the National Conference of State Legislatures (NCSL) and the National Black Caucus of State Legislatures (NBCSL). He stressed that the AIDS community needs to start looking at the States for funding rather than depending on the Federal Government.

Ms. Aragon agreed that the States are important partners, but emphasized that the magnitude of cuts that could occur if the FY 2000 budget caps are sustained would far exceed the capacity of State or local entities, and that critical services could be lost.

Services Subcommittee

The subcommittee organized Monday's access to care panel presentation. Ms. Aragon said the subcommittee would follow up with the three presenters regarding development of a broad plan to address access to care.

In addition, the subcommittee heard a presentation from Nan Roman and Randy Russell of the National AIDS Housing Coalition, which, along with NORA, is requesting a $60 million

increase for the Housing Opportunities for Persons with AIDS (HOPWA) program in FY 2000. They discussed the critical role of housing in stabilizing those with HIV and in facilitating access to care. For this reason, the subcommittee will continue to monitor HIV housing issues.

The subcommittee also discussed Ryan White reauthorization. Members would like to invite community advocates to provide an informational update on the reauthorization process during the October meeting.

Finally, Ms. Aragon said the subcommittee had scheduled its next four or five conference calls.

Other Business

Mr. Montoya reminded Council members that the next meeting will be held October 4 and 5, 1999. The Executive Committee will hold its first conference call on June 23 at 10:00 a.m. Eastern time. All subcommittee chairs must submit their conference call schedules to Mr. Montoya. Travel reimbursements must be sent in as soon as possible.

For the June 23 conference call, it is important that all subcommittee chairs submit to Mr. Montoya their agenda items for the July 13 meeting with Mr. Thurm, requests for interim Council activity before the October meeting, and requests for Council agenda time at the October meeting.

Dr. Hitt reiterated that, in his memo to Mr. Thurm, he would mention the FTE for the "Know Your Status" campaign and a timetable for the Health Care Worker Guidelines.

Regarding Council member terms, Dr. Hitt said the vetting process for new members would take a couple of months. Seventeen members' terms will end in July, five additional members' terms will expire by December, and only two members have expressed a desire to rotate off the Council. It is Dr. Hitt's understanding that vacancies will be filled by random selection. He expects a fair turnover between now and December.

The meeting was adjourned at 4:15 p.m.

Presidential Advisory Council on HIV/AIDS
Thirteenth Meeting

June 7–8, 1999

The Radisson Barcelo Hotel
Washington, DC

DRAFT AGENDA
JUNE 4, 1999

Monday, June 7

8:30 a.m.	Welcome R. Scott Hitt, M.D., Chair Update of Interim Activities	*National Gallery A&B*
9:00 a.m.	Office of National AIDS Policy Update Sandra Thurman and Todd Summers, Office of National AIDS Policy	
10:00 a.m.	Subcommittee meetings:	
	Research Subcommittee Update and Discussion on Applied Behavioral Research Judith Auerbach, Ph.D., Office of AIDS Research (NIH)	*Renwick*
	Prevention Subcommittee Update and Discussion on HIV/AIDS Prevention Issues	*Corcoran*
	Services Subcommittee Discussion on Interim Council Activities	*Hirshhorn*
12:00 p.m.	**LUNCH** (on your own)	
2:00 p.m.	Full Council Presentation "Planning Access to Care" Mike Hash, Health Care Finance Administration Daniel Mendelson, Office of Management and Budget (T) Eric Goosby, M.D., U.S. Department of Health and Human Services	*National Gallery A&B*
4:00 p.m.	**Appropriations Subcommittee** Update on HIV/AIDS Appropriations	*Hirshhorn*
	International Issues Subcommittee	*Renwick*
	Racial/Ethnic Populations Subcommittee Update on HIV/AIDS and Racial and Ethnic Populations	*Corcoran*
6:00 p.m.	**ADJOURN**	

Tuesday, June 8

8:30 a.m.	Subcommittee Meetings:	
	Appropriations Subcommittee Update on HIV/AIDS Appropriations	*Hirshhorn*
	International Issues Subcommittee Update on HIV/AIDS International Issues	*Renwick*
	Racial/Ethnic Populations Subcommittee Update on HIV/AIDS and Racial and Ethnic Populations	*Corcoran*
9:30 a.m.	**Prevention Subcommittee** Centers for Disease Control and Prevention Update on HIV/AIDS Prevention Issues Eva Seiler, M.D., Ph.D., M.P.H., Centers for Disease Control and Prevention Helene Gayle, Centers for Disease Control and Prevention	*Renwick*
	Research Subcommittee Update and Discussion on HIV/AIDS Research Issues (Vaccine Initiatives and Applied Behavioral Research)	*Corcoran*
11:00 a.m.	**Services Subcommittee** "Discussion on HIV/AIDS Housing and the HOPWA Appropriation" Randy Russell, The AIDS Task Force of Alabama Nan Roman, National Alliance to End Homelessness	*Renwick*
12:00 noon	**LUNCH** (on your own)	
2:00 p.m.	Public Comment	*National Gallery A&B*
2:45 p.m.	**BREAK**	
3:00 p.m.	Subcommittee Reports	
5:00 p.m.	Other Business	
6:00 p.m.	**ADJOURN**	

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Food and Drug Administration
Rockville MD 20857

May 27, 1999

Dear Colleague:

Enclosed are two important pieces of information. The first is information about an upcoming meeting to provide interested persons with an opportunity to provide comments that will assist in the development of an overall strategy for achieving effective regulation of dietary supplements.

Currently, there is very little FDA regulation of dietary supplements. Some feel that any further oversight by FDA would limit access to dietary supplements. Others believe that lack of regulatory oversight has led to a flood of products with no guarantee of purity or potency that can be unproven, ineffectual, and sometimes dangerous.

If you have thoughts related to regulatory oversight of dietary supplements, please submit your comments. A second, similar meeting is being considered later this summer on the west coast.

Also enclosed is information about the FDA MedWatch Program. A variety of adverse events are being experienced in the HIV patient community, which may be related to drug therapy. Although discussions and concerns about such effects may be common, for a variety of reasons, many are not reported to the FDA.

Although safety is a major concern when drugs are tested for marketing, limitations of clinical trial design, in terms of numbers of test subjects and duration of use, can mean certain events will not be detected. Adverse effects which are relatively rare, or those that occur only after long term use may not be detected. Post marketing surveillance is key to discovering such problems.

Reporting of serious side effects is important because it allows tracking and assessment of such effects, and analysis of trends that may show a connection to a particular drug therapy or drug class. Recognizing these connections can lead to changes in product labeling and safer use of marketed drug products.

If you or someone you know has experienced a serious adverse event that may be related to use of a medical product, the treating physician should be encouraged to report the event to FDA through MedWatch. If reporting by a physician is impractical, the patient may report the event directly to MedWatch.

Please share this information with your colleagues and constituents so that they are aware of these issues.

Sincerely,

Richard Klein

Enclosures

Food and Drug Administration, Office of Special Health Issues
5600 Fishers Lane, HF-12, Rockville, MD, 20857
301.827.4460 Voice / 301.443.4555 FX / Rklein@oc.fda.gov

☞ Notice of Public Meeting ☜

Dietary Supplements

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Food and Drug Administration

[Docket No. 99N-1174]

Dietary Supplements; Center for Food Safety and Applied Nutrition

Food and Drug Administration, HHS.

SUMMARY: The Food and Drug Administration (FDA) is announcing a public meeting to solicit comments that will assist the Center for Food Safety and Applied Nutrition (CFSAN) to develop an overall strategy for achieving effective regulation of dietary supplements under the Dietary Supplement Health and Education Act (DSHEA). This meeting is intended to give the public an opportunity to comment on the development of the strategy.

DATES: The meeting will be held on June 8, 1999, from 10 a.m. to 4 p.m.
Submit written comments by August 20, 1999.

ADDRESSE: The meeting will be held at
the Cohen Bldg., Auditorium, 330 Independence Ave. SW., Washington, DC.

FOR FURTHER INFORMATION CONTACT: Naomi Kulakow,
Center for Food Safety and Applied Nutrition (HFS-165), Food and Drug Administration,
200 C St. SW. Washington, DC 20204, 202-205-8682, FAX 202-260-8957,
e-mail nkulakow@bangate.fda.gov.

SUPPLEMENTARY INFORMATION:

I. *Introduction*

This meeting is the first of two meetings to seek stakeholder comments on the development of an overall strategy for achieving effective regulation of dietary supplements under the Federal Food,Drug, and Cosmetic Act, as amended by DSHEA. The meetings will build upon themes that emerged from a broader stakeholder meeting sponsoredby CFSAN in June 1998. That meeting addressed the nonfood safetyinitiative programs that are managed by CFSAN and identified some basic themes including: (1) The need to maintain a credible FDA program,including compliance, enforcement, and consumer outreach activities that will help ensure consumer confidence in FDA regulated products; (2) the need to maintain a solid, science based program staffed with highly qualified scientists; and (3) the recognition that FDA's assistance to consumers and the regulated industry is important.

II. *Registration and Requests for Oral Presentations*
If you would like to attend the meeting, you must register with the contact person (address above) by May 28, 1999, by providing your:

Name, title, business affiliation, address, telephone, and fax number.

To expedite processing, registration information may also be faxed to 202-260-8957. If you need special accommodations due to disability, please inform the contact person when you register.

If you wish to make an oral presentation during the meeting, you must inform the contact person of that desire when you register to attend and submit: (1) A brief written statement of the general nature of the evidence or arguments that you wish to present, (2) the names and addresses of the persons who will give the presentation, and (3) the approximate length of time that you are requesting for your presentation. Depending on the number of people who register to make presentations, we may have to limit the time allotted for each presentation.

III. *CFSAN's 1999 Program Priorities Document*
The meeting announced in this notice, as well as a meeting to be announced later on the west coast, are in response to CFSAN's 1999 Program Priorities document that calls for the development of an overall dietary supplement strategy in conjunction with other agency units and stakeholders. A copy of the priorities document is available on the Internet on FDA's Website at ``http://vm.cfsan.fda.gov/<difference>dms/cfsan199.html''.

The priorities document states that the overall strategy should address all elements of the dietary supplement program including: (1) Boundaries between dietary supplements and conventional foods, between dietary supplements and drugs, and between dietary supplements andcosmetic products; (2) claims; (3) good manufacturing practices; (4) adverse event reporting; (5) laboratory capability; (6) research needs; (7) enforcement; and (8) resource needs. FDA's objective in developingthis strategy is to ensure consumer access to safe dietary supplements that are truthfully and not misleadingly labeled. FDA intends to develop this strategy by following a process of openness, flexibility, efficiency, and commitment to public health.

FDA has identified four criteria for priority ranking the tasks encompassed in the strategy. These criteria are: (1) Enhancement of consumer safety, (2) development of health-related product labeling

regulation, (3) improvement in efficiency of operation, and (4) closure on unresolved regulatory issues.

This meeting also addresses activity undertaken by the agency to solicit comments in accordance with section 406(b) of the Food and DrugAdministration Modernization Act of 1997 (Pub. L. 105-115) (21 U.S.C. 393(b)).

IV. *Agenda and Goals*
To help focus comments for the June 8, 1999, meeting, FDA requests that oral and written input regarding an overall strategy for achieving effective regulation of dietary supplements address the following questions:

1. In addition to ensuring consumer access to safe dietary supplements that are truthfully and not misleadingly labeled, are there other objectives that an overall dietary supplement strategy should include?

2. Are the criteria for prioritizing the tasks within thesupplement strategy appropriate? Which specific tasks should FDA undertake first?

3. What factors should FDA consider in determining how best to implement a task (i.e., use of regulations, guidance, etc.)?

4. What tasks should be included under the various dietary supplement program elements in the CFSAN 1999 Program Priorities document?

5. Are there current safety, labeling, or other marketplace issues that FDA should address quickly through enforcement actions to ensure, for example, that consumers have confidence that the products on the market are safe and truthfully and not misleadingly labeled?

6. Toward what type or area of research on dietary supplementsshould FDA allocate its research resources?

7. Given FDA's limited resources, what mechanisms are available, or should be developed, to leverage FDA's resources to meet effectively the objective of the strategy?

V. *Comments*

Interested persons may, on or before August 20, 1999., submit written comments to the Dockets Management Branch (HFA-305), Food and Drug Administration, 5630 Fishers Lane, rm. 1061, Rockville, MD 20852. You may also send comments to the Dockets Management Branch via e-mail to ``FDA Dockets@bangate.fda.gov'' or via the FDA Website ``http://www.fda.gov''. You should annotate and organize your comments to identify the specific issues to which they refer. You must submit two copies of comments, identified with the docket number found in brackets in the heading of this document, except that you may submit one copy if you are an individual. You may review received comments in the Dockets Management Branch between 9 a.m. and 4 p.m., Monday through Friday.

VI. *Transcripts*

You may request transcripts of the meeting in writing from the Freedom of Information Office (HFI-35), Food and Drug Administration, 5600 Fishers Lane, rm. 12A-16, Rockville, MD 20857, approximately 15 working days after the meeting at a cost of 10 cents per page. You may also examine the transcript of the meeting at the Dockets Management Branch (address above) between 9 a.m. and 4 p.m., Monday through Friday, as well as on the FDA Website ``http://www.fda.gov''.

Dated: *May 6, 1999.*
William K. Hubbard,
Acting Deputy Commissioner for Policy.

MEDWATCH

The FDA Medical Products Reporting Program

MedWatch is the system through which the Food and Drug Administration monitors serious adverse health events and problems related to medications and medical devices, and by which the agency communicates new safety information to the medical community to improve patient care.

The MedWatch system enhances the effectiveness of postmarket surveillance of approved products as they are used in regular medical practice. It allows health care providers a simple and convenient way to report serious reactions and problems associated with medical products to the FDA. This, in turn, allows the FDA to identify significant health hazards associated with these products.

However, it can only be effective when heath care professionals take the time to report problems to the system. Many adverse events go unreported, and cannot be tracked or tabulated to reveal safety problems that did not appear during clinical trial studies of the product, or show specific trends or problems related to long term use.

If you or someone you know has experienced a serious adverse effect related to the use of a medical product, ask your doctor to report the experience to the FDA through the MedWatch Program. In some cases you may not wish to have the event reported by your doctor, or your doctor may be too busy to report the event to the agency. In this case, you may file a report yourself.

Reports can be made to the MedWatch Program either in writing, or over the Internet.

You or your doctor may obtain the MedWatch Voluntary Reporting Form by calling the MedWatch office toll-free at 1.800.332.1088. The one page form takes only a few moments to complete, and can be submitted by postage paid mail or via a toll-free FAX number.

You can file a report online by pointing your browser to:
https://www.accessdata.fda.gov/medwatch/medwatch-online.htm
and following reporting instructions. You can also access MedWatch using the button on the FDA homepage, located at www.fda.gov

A sample of the form is reproduced on the reverse side of this page. For forms and complete instructions for filing, please contact the MedWatch office at the number or the web site noted above.

If you have questions related to MedWatch reporting, you may contact the MedWatch staff at 800.FDA.1088, or contact Richard Klein at 301 827.4459

05-27-1999

ACCESS/QUALITY/COST - NEW YORK: TO BEGIN AMBITIOUS MEDICAID MANAGED CARE MOVE

"In one of the most ambitious efforts of its kind" nationwide, New York will begin transferring 1.1 million New York City Medicaid recipients into managed care plans, beginning in July, based on long-sought approval received yesterday from HCFA, the New York Times reports. About 400,000 New York City residents are currently voluntarily enrolled in Medicaid managed care; at $28 billion annually, the state's Medicaid program is the most expensive in the nation. The decision, which was delayed by federal review of "whether the city had a sufficiently extensive network of health plans and doctors," received mixed reviews. Officials in both the administrations of Mayor Rudolph Giuliani (R) and Gov. George Pataki (R) praised the decision as a means of saving tax dollars. "This waiver will give millions of medically needy New Yorkers the medical homes and the quality health care they need to live long healthy lives," Dennis Whalen, the acting State Health Commissioner, said. Advocates for the disabled expressed support for the move, particularly for its "careful" exclusion of chronically ill and disabled recipients. However, "the city's economically beleaguered hospitals are raising concerns" that the union of Medicaid and managed care "will cause them greater financial distress and potential ruin."

SPECIAL CONSIDERATIONS

Under the approved plan, people with chronic illnesses like AIDS and diabetes will be exempt from mandatory HMO enrollment. The city and state will also be required to conduct "an extensive public information campaign intended to alert people with AIDS and other chronic illnesses that they are exempt." Michael Kink, legislative director for Housing Works, an AIDS service organization, said, "The federal government isn't taking an 'anything goes' attitude. They are being careful. And there are plenty of good reasons to be careful when the health care of more than a million poor and disabled New Yorkers is at a stake." New York will also be required to establish an appeals process for Medicaid managed care enrollees. Enrollment will begin with lower Manhattan, parts of Brooklyn and all of Staten Island, totaling 400,000 residents, while the remainder of the city will be phased in later (Hernandez, 5/27).

- *American Healthline*

HIV/AIDS Surveillance Supplemental Report

Volume 5, Number 2

AIDS Cases Reported to CDC July 1988 through June 1998

and

Estimates of the Number of Persons Living with AIDS

by State and Metropolitan Area as of June 30, 1998

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Centers for Disease Control and Prevention
National Center for HIV, STD, and TB Prevention
Atlanta, Georgia 30333

The *HIV/AIDS Surveillance Supplemental Report* is published by the Surveillance Branch of the Division of HIV/AIDS Prevention – Surveillance and Epidemiology, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention (CDC). Data are presented on AIDS cases reported to CDC through June 30, 1998, by state and metropolitan area. The data were made available to the Health Resources and Services Administration for the allocation of Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funds. Also presented are estimates (computed by three methods) of the number of persons living with AIDS. All data in this report are provisional.

Suggested Citation:
Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Supplemental Report.* 1999;5(No. 2): [inclusive page numbers].

Single copies of the *HIV/AIDS Surveillance Supplemental Report* are available from the
CDC National Prevention Information Network (NPIN)
P.O. Box 6003
Rockville, MD 20849-6003
Telephone 1-800-458-5231 or 1-301-562-1098
http://www.cdc.gov/nchstp/hiv_aids/stats/hasrsupp.htm

Copyright Information

Methods

The Ryan White CARE Act was enacted by Congress in 1990 and reauthorized with amendments in 1996. The primary purpose of the act is to provide emergency assistance to localities that are disproportionately affected by the human immunodeficiency virus epidemic. An eligible metropolitan area (EMA) is any metropolitan area for which there have been reported to the Centers for Disease Control and Prevention (CDC) a cumulative total of more than 2,000 acquired immune deficiency syndrome (AIDS) cases for the most recent 5 years for which data are available. The amended act requires formula grants based on the estimated number of persons living with AIDS in the EMA. Estimates were derived by using methods specified in the act. The amount of funds received by each EMA (under Title I) or state (under Title II) is determined by the locality's proportion of the total estimated number of living persons with AIDS.

As of the end of June each year, AIDS cases reported during the preceding 120 months are aggregated into ten 12-month periods, and 10 "survival" weights (see Technical Notes) are applied to the 10 AIDS case counts. The summary count, which results from this computational formula, is the estimated number of persons living with AIDS in the EMA or state for the purposes of the Ryan White CARE Act. The survival weights are updated by CDC every 2 years according to methods specified in the act (the weights were most recently updated in July 1997).

This report presents the AIDS case counts (based on AIDS surveillance data reported to CDC through June 30, 1998) that were provided to the Health Resources and Services Administration (HRSA) in July 1998. (Table 1, AIDS case counts by state; Table 2, AIDS case counts by EMA; Table 3, AIDS case counts for cross-state EMAs). HRSA applies the weights provided by CDC to these counts to determine the proportional distribution of persons living with AIDS.

Tables 4 and 5 are comparisons of the three methods for estimating the number of persons living with AIDS by state and EMA. Columns 1 and 2 are the estimated number and the percentage distribution according to the Ryan White CARE Act formula. Columns 3 and 4 are the numbers of persons with AIDS reported to CDC and presumed to be alive (cases minus deaths). Columns 5 and 6 are data adjusted for delays in the reporting of cases and deaths to produce point estimates of the number of persons living with AIDS. (See the Technical Notes for computational details of each method.)

The Ryan White CARE Act formula is used by HRSA for the legislative requirements of the CARE act. CDC, however, routinely adjusts data for reporting delays to estimate the number of persons living with AIDS (i.e., AIDS prevalence; see HIV/AIDS Surveillance Supplemental Report, 1999;5[no.1]). The CDC method nearly always produces the highest counts because a statistical model is used to "add in" the AIDS cases not yet reported but already diagnosed.

Table 1. AIDS cases reported July 1988 through June 1998, by state of residence

State of residence	7/88-6/89	7/89-6/90	7/90-6/91	7/91-6/92	7/92-6/93	7/93-6/94	7/94-6/95	7/95-6/96	7/96-6/97	7/97-6/98
Alaska	16	29	16	14	29	73	79	37	44	41
Alabama	224	204	318	425	702	557	565	663	523	603
Arkansas	78	116	220	197	423	289	286	284	242	225
Arizona	260	370	237	366	1,098	645	559	650	529	548
California	5,995	6,791	7,352	8,398	15,075	14,171	10,824	10,459	8,108	6,336
Colorado	345	380	442	424	1,081	882	715	597	430	317
Connecticut	424	435	479	480	1,461	1,302	1,055	1,511	1,201	894
District of Columbia	535	535	712	813	1,077	1,575	1,216	1,051	1,191	943
Delaware	83	83	90	106	307	258	309	318	264	161
Florida	3,115	3,969	4,865	5,194	9,005	7,655	9,239	7,673	6,685	5,489
Georgia	994	1,219	1,197	1,729	2,237	2,235	2,294	2,486	2,107	1,362
Hawaii	115	190	185	166	201	316	263	207	144	128
Iowa	57	48	89	86	189	98	144	128	104	97
Idaho	20	23	23	39	66	55	57	44	44	39
Illinois	1,032	1,228	1,215	1,835	2,811	2,726	2,755	2,145	1,748	1,782
Indiana	235	328	283	378	757	725	521	651	562	487
Kansas	95	133	115	168	296	254	257	256	178	147
Kentucky	106	150	185	179	295	298	309	314	402	312
Louisiana	425	659	696	915	1,166	1,222	1,109	1,355	1,224	1,064
Massachusetts	771	816	944	861	1,909	2,023	1,367	1,294	1,117	784
Maryland	609	871	1,016	1,033	1,984	2,210	2,885	2,272	2,155	1,629
Maine	43	67	50	56	78	137	139	80	55	41
Michigan	504	528	574	841	1,543	1,076	1,057	1,033	940	804
Minnesota	173	173	200	238	588	382	406	322	246	177
Missouri	376	563	577	707	1,623	813	677	848	690	543
Mississippi	123	214	261	226	384	411	411	413	447	359
Montana	30	16	30	22	26	29	24	30	42	34
North Carolina	366	519	528	649	1,002	1,296	1,013	977	858	812
North Dakota	2	2	13	1	10	28	6	10	10	10
Nebraska	40	41	65	61	151	106	112	98	97	77
New Hampshire	43	57	46	53	89	90	115	99	68	60
New Jersey	2,382	2,233	2,419	2,193	3,408	5,202	4,724	3,980	3,753	2,507
New Mexico	78	102	109	108	279	164	229	113	229	220
Nevada	137	170	225	248	537	429	412	455	465	484
New York	6,368	7,642	7,678	7,976	13,968	15,077	12,537	13,226	12,472	11,329
Ohio	532	587	596	800	1,164	1327	1,181	1,108	937	785
Oklahoma	160	216	172	241	655	347	269	278	288	298
Oregon	197	276	288	290	658	577	506	500	356	234
Pennsylvania	1,013	1,149	1,094	1,392	2,134	2,810	2,661	2,256	2,124	1,897
Rhode Island	84	93	76	121	231	274	286	180	160	141
Puerto Rico	1,391	1,467	1,737	1,754	2,579	2,603	2,544	2,128	2,207	2,020
South Carolina	246	367	344	354	1,128	1,173	985	954	801	777
South Dakota	6	1	9	9	23	17	20	17	9	17
Tennessee	283	307	329	410	851	848	876	899	791	694
Texas	2,327	2,802	3,053	3,198	6,075	5,807	5,083	4,352	4,882	4,472
Utah	79	86	108	129	278	136	152	198	158	150
Virginia	392	610	645	659	1,360	1,368	1,140	1,506	1,253	999
Virgin Islands	28	7	12	21	47	40	58	33	55	64
Vermont	14	19	21	22	26	81	31	40	33	21
Washington	443	694	591	533	1,171	1,181	922	770	758	528
Wisconsin	115	179	197	224	623	399	358	325	252	222
West Virginia	38	62	51	72	76	79	113	146	113	130
Wyoming	14	7	11	11	34	20	14	15	17	5

Table 2. AIDS cases reported July 1988 through June 1998, by metropolitan area of residence

Metropolitan area of residence	7/88-6/89	7/89-6/90	7/90-6/91	7/91-6/92	7/92-6/93	7/93-6/94	7/94-6/95	7/95-6/96	7/96-6/97	7/97-6/98
Atlanta, GA	773	944	941	1,232	1,528	1,501	1,605	1,762	1,415	942
Austin, TX	151	229	200	275	481	527	385	292	275	297
Baltimore, MD	401	580	668	594	1,384	1,468	2,019	1,508	1,516	1,093
Bergen-Passaic, NJ	247	275	284	270	402	787	612	490	513	330
Boston, MA-NH	721	741	813	763	1,694	1,754	1,192	1,128	945	702
Caguas, PR	74	135	102	132	180	187	205	173	175	152
Chicago, IL	910	1,070	1,034	1,592	2,432	2,361	2,451	1,807	1,432	1,567
Cleveland, OH	142	123	166	250	363	340	470	244	279	271
Dallas, TX	546	626	786	780	1,634	1,168	1,410	1,001	897	808
Denver, CO	284	308	373	351	914	677	566	447	325	247
Detroit, MI	354	375	382	645	1,086	660	773	725	572	594
Dutchess Co., NY	51	83	79	84	146	118	91	113	108	158
Fort Lauderdale, FL	449	845	846	853	1,064	1,119	1,579	1,217	1,121	826
Fort Worth, TX	137	167	188	145	367	319	538	199	306	259
Hartford, CT	131	153	162	142	425	586	387	513	414	343
Houston, TX	844	1,127	1,172	1,176	2,136	2,075	1,323	1,323	1,793	1,759
Jacksonville, FL	151	239	275	296	782	336	473	384	363	295
Jersey City, NJ	408	283	420	359	412	774	881	631	603	398
Kansas City, MO-KS	199	323	236	292	721	337	286	344	216	222
Las Vegas, NV-AZ	103	135	178	191	426	333	338	373	381	433
Los Angeles, CA	2,129	2,132	2,549	3,018	5,083	4,664	3,903	3,834	3,175	2,248
Miami, FL	946	1,077	1,540	1,654	2,409	2,864	2,924	2,355	1,789	1,562
Middlesex-Somerset-Hunterdon, NJ	182	157	192	193	320	360	381	329	259	198
Minneapolis-St. Paul, MN-WI	157	160	173	205	526	328	364	278	218	160
Nassau-Suffolk, NY	322	411	355	308	943	569	549	639	655	456
New Haven, CT	255	249	289	297	913	614	580	848	671	495
New Orleans, LA	264	388	428	543	605	699	607	727	635	505
New York, NY	5,552	6,416	6,604	6,915	11,424	13,391	10,741	11,275	10,084	8,711
Newark, NJ	1,034	984	945	927	1,265	2,120	1,734	1,525	1,545	1,008
Norfolk, VA-NC	87	159	148	118	273	371	388	544	490	326
Oakland, CA	331	534	506	570	1,091	962	742	663	546	410
Orange County, CA	262	334	339	597	583	567	537	512	357	287
Orlando, FL	192	191	396	358	859	431	740	589	495	524
Philadelphia, PA-NJ	758	833	834	1,042	1,724	2,256	2,012	1,687	1,586	1,466
Phoenix, AZ	185	285	170	275	772	431	392	457	329	392
Ponce, PR	197	217	241	247	254	333	309	284	221	161
Portland, OR-WA	174	227	254	234	609	443	398	354	266	184
Riverside-San Bernardino, CA	213	255	320	404	884	959	816	654	558	562
Sacramento, CA	169	113	175	261	404	432	348	277	210	195
St. Louis, MO-IL	185	213	310	376	768	443	376	437	416	279
San Antonio, TX	348	195	190	230	329	632	380	373	367	309
San Diego, CA	450	719	555	605	1,389	1,219	946	1,138	809	640
San Francisco, CA	1,739	1,929	2,082	1,969	3,744	3,386	2,126	1,774	1,363	1,158
San Jose, CA	155	144	190	176	398	478	297	295	216	143
San Juan, PR	916	951	1,119	1,062	1,732	1,569	1,529	1,300	1,377	1,258
Santa Rosa, CA	127	96	121	117	221	224	130	169	76	57
Seattle, WA	330	536	436	382	901	769	650	539	492	339
Tampa-St. Petersburg, FL	439	380	473	517	1,299	776	817	752	655	618
Vineland-Millville-Bridgeton, NJ	38	36	35	28	77	104	68	101	62	46
Wash., DC-MD-VA-WV	867	1,000	1,281	1,470	2,023	2,733	2,138	2,063	2,010	1,666
West Palm Beach, FL	321	343	398	438	827	583	857	831	723	549

Table 3. AIDS cases reported July 1988 through June 1998, for state components of cross-state metropolitan areas

Metropolitan area of residence	7/88-6/89	7/89-6/90	7/90-6/91	7/91-6/92	7/92-6/93	7/93-6/94	7/94-6/95	7/95-6/96	7/96-6/97	7/97-6/98
Boston, MA	692	699	781	732	1,632	1,694	1,116	1,065	900	654
Boston, NH	29	42	32	31	62	60	76	63	45	48
Kansas City, KS	44	66	46	52	135	95	82	92	56	57
Kansas City, MO	155	257	190	240	586	242	204	252	160	165
Las Vegas, AZ	5	4	3	4	18	8	11	12	11	16
Las Vegas, NV	98	131	175	187	408	325	327	361	370	417
Minneapolis-St. Paul, MN	155	158	172	204	524	326	364	277	217	159
Minneapolis-St. Paul, WI	2	2	1	1	2	2	0	1	1	1
Norfolk, NC	0	2	2	0	1	0	0	3	2	2
Norfolk, VA	87	157	146	118	272	371	388	541	488	324
Philadelphia, NJ	127	146	143	159	278	332	302	248	244	183
Philadelphia, PA	631	687	691	883	1,446	1,924	1,710	1,439	1,342	1,283
Portland, OR	158	213	234	221	550	403	362	331	230	158
Portland, WA	16	14	20	13	59	40	36	23	36	26
St. Louis, IL	28	27	37	53	74	47	63	47	43	32
St. Louis, MO	157	186	273	323	694	396	313	390	373	247
Washington, DC	535	535	712	813	1,077	1,575	1,216	1,051	1,191	943
Washington, MD	178	250	294	385	491	620	616	580	531	428
Washington, VA	149	209	270	267	440	530	292	408	275	281
Washington, WV	5	6	5	5	15	8	14	24	13	14

Table 4. Estimates of the number of people living with AIDS as of June 1998, by state of residence: comparison of three methods

State of Residence	Ryan White CARE Act Number*	Ryan White CARE Act Percent	Number reported to be living Number†	Number reported to be living Percent	Adjusted for reporting delays Number†	Adjusted for reporting delays Percent
Alaska	151	0.1	214	0.1	221	0.1
Alabama	1,856	0.9	2,404	0.9	2,520	0.9
Arkansas	843	0.4	1,258	0.5	1,321	0.5
Arizona	1,892	0.9	2,151	0.8	2,632	0.9
California	30,434	14.2	38,264	14.6	41,965	14.7
Colorado	1,766	0.8	2,524	1.0	2,499	0.9
Connecticut	3,634	1.7	5,040	1.9	5,502	1.9
Distnct of Columbia	3,586	1.7	4,816	1.8	5,156	1.8
Delaware	780	0.4	946	0.4	982	0.3
Florida	22,618	10.5	29,246	11.2	30,909	10.9
Georgia	6,442	3.0	8,436	3.2	9,026	3.2
Hawaii	617	0.3	770	0.3	845	0.3
Iowa	369	0.2	497	0.2	508	0.2
Idaho	148	0.1	179	0.1	181	0.1
Illinois	6,784	3.2	7,502	2.9	8,139	2.9
Indiana	1,822	0.8	2,343	0.9	2,472	0.9
Kansas	665	0.3	794	0.3	808	0.3
Kentucky	1,037	0.5	1,182	0.5	1,306	0.5
Louisiana	3,759	1.7	4,522	1.7	4,664	1.6
Massachusetts	3,923	1.8	4,546	1.7	5,347	1.9
Maryland	6,610	3.1	7,608	2.9	8,737	3.1
Maine	247	0.1	371	0.1	375	0.1
Michigan	3,129	1.5	3,768	1.4	4,223	1.5
Minnesota	943	0.4	1,328	0.5	1,390	0.5
Missouri	2,390	1.1	3,537	1.4	3,694	1.3
Mississippi	1,271	0.6	1,445	0.6	1,505	0.5
Montana	106	0.0	138	0.1	152	0.1
North Carolina	2,971	1.4	3,415	1.3	3,764	1.3
North Dakota	35	0.0	39	0.0	41	0.0
Nebraska	307	0.1	376	0.1	391	0.1
New Hampshire	259	0.1	419	0.2	434	0.2
New Jersey	11,786	5.5	13,031	5.0	13,953	4.9
New Mexico	630	0.3	761	0.3	867	0.3
Nevada	1,436	0.7	1,863	0.7	1,942	0.7
New York	40,078	18.6	44,665	17.1	49,911	17.5
Ohio	3,224	1.5	3,546	1.4	3,875	1.4
Oklahoma	993	0.5	1,335	0.5	1,454	0.5
Oregon	1,301	0.6	1,724	0.7	1,807	0.6
Pennsylvania	7,014	3.3	8,436	3.2	9,336	3.3
Rhode Island	599	0.3	771	0.3	813	0.3
Puerto Rico	7,230	3.4	7,878	3.0	8,494	3.0
South Carolina	2,782	1.3	3,469	1.3	3,570	1.3
South Dakota	49	0.0	56	0.0	60	0.0
Tennessee	2,498	1.2	3,250	1.2	3,449	1.2
Texas	15,387	7.2	19,781	7.6	21,676	7.6
Utah	530	0.2	724	0.3	771	0.3
Virginia	3,848	1.8	4,351	1.7	5,032	1.8
Virgin Islands	159	0.1	189	0.1	212	0.1
Vermont	111	0.1	152	0.1	163	0.1
Washington	2,518	1.2	3,419	1.3	3,676	1.3
Wisconsin	971	0.5	1,352	0.5	1,391	0.5
West Virginia	372	0.2	419	0.2	444	0.2
Wyoming	45	0.0	58	0.0	54	0.0
Total	**214,955**		**261,308**		**284,659**	

*Cumulative from July 1988 through June 1998
†Cumulative from 1981 through June 1998

Table 5. Estimates of the number of people living with AIDS as of June 1998, by metropolitan area of residence: comparison of three methods

Metropolitan area of residence (year of initial eligibility)	Ryan White CARE Act Number*	Ryan White CARE Act Percent	Number reported to be living Number†	Number reported to be living Percent	Adjusted for reporting delays Number†	Adjusted for reporting delays Percent
Atlanta, GA (1991)	4,471	2.8	5,929	3.1	6,330	3.0
Austin, TX (1995)	1,072	0.7	1,354	0.7	1,469	0.7
Baltimore, MD (1992)	4,498	2.9	5,040	2.6	5,939	2.8
Bergen-Passaic, NJ (1994)	1,553	1.0	1,681	0.9	1,828	0.9
Boston, MA-NH (1991)	3,423	2.2	4,096	2.1	4,799	2.3
Caguas, PR (1995)	556	0.4	589	0.3	615	0.3
Chicago, IL (1991)	5,836	3.7	6,336	3.3	6,859	3.3
Cleveland, OH (1996)	973	0.6	1,229	0.6	1,321	0.6
Dallas, TX (1991)	3,295	2.1	4,536	2.4	4,886	2.3
Denver, CO (1994)	1,378	0.9	1,984	1.0	1,944	0.9
Detroit, MI (1993)	2,150	1.4	2,600	1.4	2,860	1.4
Dutchess Co., NY (1995)	393	0.3	464	0.2	503	0.2
Fort Lauderdale, FL (1991)	3,585	2.3	4,490	2.3	4,787	2.3
Fort Worth, TX (1996)	972	0.6	1,285	0.7	1,387	0.7
Hartford, CT (1996)	1,311	0.8	1,778	0.9	1,947	0.9
Houston, TX (1991)	5,356	3.4	6,815	3.6	7,537	3.6
Jacksonville, FL (1995)	1,221	0.8	1,851	1.0	1,901	0.9
Jersey City, NJ (1991)	1,896	1.2	2,034	1.1	2,161	1.0
Kansas City, MO-KS (1994)	955	0.6	1,526	0.8	1,567	0.8
Las Vegas, NV-AZ (1999)	1,196	0.8	1,568	0.8	1,640	0.8
Los Angeles, CA (1991)	10,932	7.0	13,212	6.9	14,572	7.0
Miami, FL (1991)	6,785	4.3	8,684	4.5	9,201	4.4
Middlesex-Somerset-Hunterdon, NJ (1996)	909	0.6	1,053	0.6	1,101	0.5
Minneapolis-St. Paul, MN-WI (1996)	833	0.5	1,168	0.6	1,227	0.6
Nassau-Suffolk, NY (1993)	1,862	1.2	2,155	1.1	2,513	1.2
New Haven, CT (1994)	2,014	1.3	2,858	1.5	3,126	1.5
New Orleans, LA (1993)	1,979	1.3	2,473	1.3	2,528	1.2
New York, NY (1991)	33,117	21.1	37,049	19.4	41,241	19.7
Newark, NJ (1991)	4,664	3.0	5,053	2.6	5,492	2.6
Norfolk, VA-NC (1999)	1,276	0.8	1,322	0.7	1,566	0.7
Oakland, CA (1992)	2,035	1.3	2,584	1.4	2,804	1.3
Orange County, CA (1993)	1,405	0.9	2,136	1.1	2,250	1.1
Orlando, FL (1994)	1,784	1.1	2,307	1.2	2,445	1.2
Philadelphia, PA-NJ (1991)	5,355	3.4	6,614	3.5	7,212	3.5
Phoenix, AZ (1994)	1,303	0.8	1,480	0.8	1,838	0.9
Ponce, PR (1993)	798	0.5	997	0.5	1,052	0.5
Portland, OR-WA (1995)	1,008	0.6	1,384	0.7	1,455	0.7
Riverside-San Bernardino, CA (1994)	2,090	1.3	2,750	1.4	2,934	1.4
Sacramento, CA (1996)	865	0.6	1,030	0.5	1,120	0.5
St. Louis, MO-IL (1994)	1,277	0.8	1,707	0.9	1,779	0.9
San Antonio, TX (1995)	1,201	0.8	1,584	0.8	1,703	0.8
San Diego, CA (1991)	2,912	1.9	3,750	2.0	4,008	1.9
San Francisco, CA (1991)	6,079	3.9	7,537	3.9	8,594	4.1
San Jose, CA (1996)	820	0.5	1,119	0.6	1,170	0.6
San Juan, PR (1991)	4,478	2.8	4,756	2.5	5,174	2.5
Santa Rosa, CA (1995)	390	0.2	563	0.3	585	0.3
Seattle, WA (1993)	1,716	1.1	2,365	1.2	2,521	1.2
Tampa-St. Petersburg, FL (1993)	2,326	1.5	3,107	1.6	3,281	1.6
Vineland-Millville-Bridgeton, NJ (1995)	220	0.1	262	0.1	265	0.1
Wash., DC-MD-VA-WV (1991)	6,387	4.1	8,199	4.3	8,854	4.2
West Palm Beach, FL (1994)	2,221	1.4	2,837	1.5	2,990	1.4
Total	**157,131**		**191,280**		**208,881**	

* Cumulative from July 1988 through June 1998
† Cumulative from 1981 through June 1998

Technical Notes

The legislative authority for the method of estimating the number of persons living with AIDS under Title I of the Ryan White CARE Act is Section 2603(a)(3)(c). The legislative authority for the Title II estimation of the number of persons living with AIDS is Section 2618(2)(d). The same set of survival weights is used for both Title I and Title II. The current weights are —

Year 1 – .07
Year 2 – .09
Year 3 – .10
Year 4 – .13
Year 5 – .15
Year 6 – .29
Year 7 – .41
Year 8 – .55
Year 9 – .71
Year 10 – .83

For each 12-month reporting period, the proportion of persons reported with AIDS and presumed to be alive is computed as follows:

(cases minus deaths)/cases

This proportion is the weight for the 12-month period.

As required by the CARE act, these weights will be updated in July 1999 by using the AIDS cases reported through June 30, 1999.

Details for the Three Methods of Estimating the Number of Persons Living with AIDS

Method I — Ryan White CARE Act formula

The counts of reported AIDS cases for the last 120 months are aggregated into ten 12-month periods. The first year (i.e., earliest) count is multiplied by .07. The second year count is multiplied by .09, and so on for all 10 counts. The total of these 10 weighted counts is the estimated number of people living with AIDS for a given state or EMA.

Method II — Number of persons reported to be living with AIDS

For each state or EMA, the number of persons reported with AIDS who are presumed to be alive is calculated. (See HIV/AIDS Surveillance Report, 1998;10[no.1]: Table 1, p.5). This total count is the number of persons living with AIDS.

Method III — Adjustments for reporting delays

Estimated AIDS data are adjusted for reporting delays by a maximum likelihood statistical procedure; differences in reporting delays for geographic area, racial/ethnic, age, sex, vital status, and exposure categories are taken into account, but it is assumed that reporting delays within these groups have not changed over time (*Statistics in Medicine* 1998;17:143-54 and *Lecture Notes in Biomathematics* 1989;83:58-88). The maximum likelihood procedure is done twice — first for delays in reporting AIDS cases and then for delays in reporting AIDS deaths. On the basis of the results of these procedures, each AIDS case is then assigned an AIDS incidence adjustment weight and an AIDS death adjustment weight. The point estimate of the number of persons living with AIDS is derived by subtracting the estimated cumulative number of deaths of persons with AIDS from the estimated cumulative number of persons with a diagnosis of AIDS. The estimates from this method are based on AIDS surveillance data for cases diagnosed with AIDS through June 30, 1998, and reported to CDC through December 31, 1998. Estimated AIDS cases and estimated AIDS deaths are adjusted for reporting delays, but not for incomplete reporting.

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DEATH SENTENCE?
By making condoms contraband, prisons may be exacerbating the AIDS health crisis.

BY DAWN MACKEEN

May 20, 1999 | Jesse Wells sits in his red shirt and matching pants, in an interview room in San Francisco County Jail, thinking of the words he wants to use. Sometimes he mumbles. Sometimes he veers into the vulgar, pardoning his expression when he does so. Wells, also known as inmate No. 1654096, is a big guy, 6 feet tall and 200 pounds. He has an imposing presence -- until he starts to speak.

"Most of the people I had sex with are dead and gone. I pray every night. It was a blessing that I didn't get it," he says. He's a bisexual who has been in and out of jail since 18, and many of the partners with whom he had unprotected sex were fellow inmates. Wells has had a 10-year relationship with a cellmate he called his "wife;" he's had sex with men

Whirling dervish
Sex freak Lisa Carver reaches for respectability.
By Virginia Vitzthum
[05/18/99]

As tears go by
Researchers collect tears, asking, "Why do we cry?"
By Susan McCarthy
[05/17/99]

Sexpert Opinion
Fallen angels
Anti-porn crusaders have given up trying to save women. Now it's just kids they want to protect.
By Susie Bright
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Healing heat
Steam and massage are part of an ancient purifying ritual.
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cellmate he called his "wife;" he's had sex with men he scarcely knew and sex with those he's certain were HIV-positive. On this March evening, as he awaits sentencing for a string of at-gunpoint robberies, he's still playing Russian roulette, not asking his lovers each week if they are infected or not. "Some people don't want to tell you that they have AIDS because they might get beaten up," he explains. "There's a lot of diseases in this place. And a lot don't know what they've got."

After watching so many of his fellow inmates die, he says he has become wiser about HIV. He uses a condom whenever he can get one, which is about once every other week. It's not enough, but Wells is better off than most of the nation's inmates. San Francisco is one of six places in the United States (the others are Vermont and Mississippi, and the cities of Washington, New York and Philadelphia) where condoms are distributed. In the rest of the country's prisons and jails, the condom is contraband. In some prisons, there is even a small black market for them -- going for about $10 apiece, says one ex-con.

The problem with all this is pretty basic, say AIDS activists and health officials: Inmates are having unprotected sex where there are six times more HIV/AIDS cases than in the general population, according to a 1995 report by the U.S. Department of Justice. Another more recent report estimates that the prison population has doubled in the last 12 years to 1.8 million. Inmates live, eat and breathe in close quarters, sharing everything from shower areas to food from the commissary to sleeping quarters. Compounding the problem is the fact that most of those incarcerated eventually get out and return to their communities -- which means from a public health perspective, their problem is our problem.

"Corrections could be where the next major health crisis is going to be, but it's not just about HIV and Hepatitis C," says John Miles of the Centers for Disease Control and Prevention. "This is a population that has been out on the streets, and hasn't had the health care that most of us have had. It's a context where we can access people who have been ill-served. If we don't take advantage of that, corrections could become a health crisis."

To many AIDS activists and prisoner advocacy groups, there's no need to wait for the Big Crisis to arrive. They say it's already here. Even the international community has recognized the problem. The major worldwide health organizations have called for condom distribution in prisons, and many countries, primarily in Europe, have listened.

"The reality is that condoms save lives because they're known as an HIV barrier," says Romeo Sanchez, director of the prison project of the Latino Commission on AIDS. "Because a person goes to prison doesn't mean that they stop having sex. There are marriages in prison, prostitution, prisoners having sex with prisoners, prisoners having sex with prison guards, documented cases of women becoming pregnant in prison -- which shows that the male guards are having sex, too."

In February, Sanchez's nonprofit group released the results of a survey of 108 former inmates of New York state prisons. Sixty-three percent said they had seen prisoners having sex; 31 percent reported knowing someone who became infected in prison through unprotected sex. But since most inmates are not tested both when they arrive and before they're released, it's difficult to estimate the actual rate of infection.

"We do not have an HIV 'health crisis' in the federal prison system," responds Dave Good, national health systems administrator for the Federal Bureau of Prisons. In the last 10 years, despite the increased number of those incarcerated, Good says the number of those who have tested positive has remained steady at 1 percent.

He attributes this to the bureau's infectious disease education program, which teaches prisoners about the dangers of, among other things, illegal needle use and sexual activity. And while activists will point the finger at agencies like the BOP if a prisoner gets infected, Good places the culpability on the inmate who makes the decision to have sex. "Inmates are responsible for their own actions. If an inmate has sexual relations or participates in illegal blood exposures, then they are putting themselves at risk."

Many health officials say the number of HIV/AIDS cases is much higher than the figure Good cites, since not all prisons and jails test inmates. In fact, in many places, it's a voluntary test -- one that inmates aren't rushing to take, because if they test positive, they might be stigmatized or put in a special HIV wing.

And even in the HIV wing, there are risks, like picking up a new strain or another disease, says Jerry Larson, an ex-con who is HIV-positive. While he and others sometimes used cut-up surgical gloves as protection, they had what amounted to unprotected sex. Larson, recently released after serving four years at Vacaville and San Quentin for holding another person captive, considers himself lucky. "I find it revolting that they know what's going on and are just ignoring it. You're talking about a group of people with years of their lives spent inside. You aren't going to get abstinence, so you've got to do something."

Next page | **Condoms as a strangulation device**

Illustration by Scott Laumann

Other countries are doing something. Canada, for example, distributes condoms in all federal prisons -- in the shower areas (a popular place to have sex), in the canteen and in the entranceways to health services. Needles, bleach and dental dams are also provided. (Canada's federal system, unlike the United States', is reserved for those sentenced to more than two years.)

"Let's just say that condoms are available in all countries in the Western industrialized world, with very few exceptions, and the United States is the big gap on the map," says Ralf Jurgens, executive director of the Canadian HIV/AIDS Legal Network, and coordinator of the Canadian government's 1994 study on the topic. In fact, Australia and most European countries distribute condoms, and international organizations from the World Health Organization to the United Nations AIDS program to the president's own advisory committee on AIDS have recommended it.

The CDC advises condom use for everyone who is sexually active, although it has never issued a formal recommendation for the incarcerated community. So why, given the HIV/AIDS rates in penal institutions, is the use of condoms by the incarcerated one of the most contentious issues facing corrections departments in the United States?

"Internationally it's seen as a pragmatic measure because of HIV and the fact that we know that many prisoners engage in sexual activity," says Jurgens. "Often the argument in the U.S. is that, 'We can't condone sexual activity behind bars.' Some people say not making condoms available is condoning the *spread* of HIV behind prison walls."

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The problem is more complex for corrections officials, who see condoms as a security threat and a penal conundrum. First the conundrum: Sex is outlawed in prisons, so "we would be saying 'Don't do this,' but 'Here is something to use'" if they do, says Carole Young, vice chairman of the Texas Board of Criminal Justice. When looking at the issue of HIV/AIDS in the Texas prison system in 1997, Young was on a committee that looked at prevention methods and decided not to condone condoms. "I don't think there's a public health crisis going on in our facilities," says Young. "Prisoners are at the highest risk of getting HIV in the population. There is no question about that. While we would not rule [condom distribution] out forever, we felt that the downside was greater than the positive, and making this available would create another set of problems."

The other worry is security. In a jail or prison setting, corrections officials say, those thin, tubular pieces of latex are dangerous. Prisoners are creative with almost everything they get, and could use condoms as strangulation devices, sling shots, fingerprint barriers or drug-stashing vehicles.

"I would not be concerned about it as a weapon, but I would as far as drugs are concerned," says Bob Houston, warden of Douglas County Correction Center in Omaha, Neb. "They could use it like a balloon. We've had visitors put the drugs in a balloon in their mouth and then kiss the inmate, or pass it through some other way, and the inmate swallows it. At the end of the visit, the inmate can successfully go through the strip search and then vomit it up at a later point."

Even in facilities where condoms are offered, they aren't being handed out in every cell. Some make them available at commissaries; others give one out only after the inmate goes through an HIV/AIDS education program. Each facility tends to do it differently. In Mississippi, where condoms have been distributed for years because of the state's conjugal visit policy, their presence is almost a non-issue with prison officials. "It's an item, like chewing gum or candy bars," says Ken Jones nonchalantly. Jones, spokesman for the Mississippi Department of Corrections, says condoms are not

the hottest commodity for sale at the canteens. In the last quarter of1998, they sold only 30 packs of three condoms each.

Washington was the last place to authorize distribution, in 1992. And the BOP does not foresee changing its policy in the future. "The issue is a political hot potato," says Nic Howell, spokesman for the Illinois Department of Corrections. "I think my neighbors would go absolutely ape-shit if they even suspected that we were providing inmates with condoms. It would be construed by the taxpayer that we were urging them to have sex. And believe me, the next director of corrections would not allow condoms to be distributed, because it wouldn't be long that before the director of corrections who allowed that to happen would be looking for a job."

So getting support for distribution has been difficult. In the mid-'80s, San Francisco Sheriff Michael Hennessey struggled to make them available in San Francisco County, where he oversees seven jails. Many of his deputies had AIDS. Hennessey wanted to do something to stem the disease's spread.

Getting permission was harder than he thought. He was bounced back and forth between local attorneys and the state attorney general, and never did get a "green light," as he calls it, but only a "yellow" one. The district attorney told him to walk a fine legal line: It was not a crime to distribute condoms, but it could be if a staff person handed a condom to someone knowing that the person intended to use it to have sex. Hennessey had a staff official quit over the issue, but looking back more than 10 years later, he says it was worth it. "People had all kinds of fears about what it would lead to -- promiscuous sex, sexual assault, condoms used to smuggle drugs, or to strangle someone. There were all those fears and concerns, but frankly, none of them have happened. We've probably distributed between 20-25,000 condoms and we've never had anyone misuse one in those illegal fashions."

Even in San Francisco, many inmates said they did not know condoms were available. "I'm HIV-positive and I didn't know that they gave them out here," says 35-year-old Terry Havro, who tested positive while at San Quentin 10 years ago.

Jackie Walker, AIDS information coordinator for the ACLU National Prison Project, receives letters from inmates all over the country who claim to have become infected after having sex with another prisoner. The stories, she says, basically mirror those on the outside -- they had sex, didn't know the other person was infected, then they test positive. But, she says, there is a big difference between what happens on the inside and the outside. "Prisons are the only place in the community where you can't protect yourself," Walker says. "There's no way you could practice this idiotic reasoning except with prisoners. That should not be the attitude -- these folks will be returning to the community."

In fact, according to Hennessey, 98 percent of the inmate population gets out again, going back to their lovers, homes, neighborhoods, friends, wives, boyfriends and girlfriends, not to mention meeting new ones. It's a statistic he calls "one of the best-kept secrets of the criminal justice system."

"You don't see that on TV," says Hennessey. "You see people arrested in the news, or on television shows, you see people walked away and given sentences. But the fact of the matter is almost all of them eventually get out and come back into the various communities. People come out who either obtained the disease in prison or were diseased before they were in prison and now they're getting back out, and I think it's to the community's benefit to understand better how to prevent the spread of disease."

Jerry Larson is a perfect example of that. He's been out for nine months now, and has continued to have sex. Of course, he says he uses a condom now because he can buy one. But the time inside without them continues to haunt and infuriate him. "I consider it the most foolish thing I've ever witnessed. You have the power to prevent the spreading of diseases or [the introduction of] new diseases. Especially since these people are going to take it home to their families. Just because someone said years ago that it wouldn't happen, or shouldn't happen, doesn't mean it's not going to. This disease doesn't stop at the prison door."

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About the writer
Dawn MacKeen is an associate editor for Salon Health & Body.

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05-25-1999

IN THE COURTS - ABBOTT V. BRAGDON: HIGH CT. TURNS AWAY HIV+ ADA APPEAL

The U.S. Supreme Court yesterday turned away without comment an appeal brought by dentist Randon Bragdon in a case that established Americans With Disabilities Act protection for HIV-positive people, AP/Foster's Daily Democrat reports. Although the Supreme Court decided last June that HIV falls under the umbrella of the ADA, the High Court then left open the issue of whether providing routine dental care for HIV-positive patients is safe. In December, the U.S. appeals Court ruled that the CDC's guidelines for universal precautions were sufficient to render the risk of transmitting the virus insignificant and in compliance with the American Dental Association's guidelines. As a result, the 1st U.S. Circuit Court of Appeals ruled that Sidney Abbott's legal victory in her discrimination case against Bragdon "should stand and that no trial was necessary." In Bragdon's second appeal to the Supreme Court, Bragdon implored the court to reverse the decision, arguing that the appeals court ruling "encourages health care workers to practice below-minimum safety standards." Bragdon's case was turned away, with Abbott's lawyers hailing the latest action as "the final chapter in a long history of litigation in which every court has taken the view that there is no basis, medical or otherwise, to refuse health services to people with AIDS" (Carelli, AP/Foster's Daily Democrat, 5/24). The Gay & Lesbian Advocates & Defenders applauded the move, calling it "the final chapter in a long history of this case, which established that health care providers cannot refuse critical services to patients with HIV based upon unscientific beliefs about HIV transmission" (GLAD release, 5/24).

DISABLED WORKERS

In another case, the Supreme Court yesterday unanimously voted to overturn a lower court's ruling that the Social Security Act, which provides benefits for at least one year to individuals whose disabilities prevent them from working, and the Americans with Disabilities Act, which "protects disabled workers from discrimination as long as they can perform their jobs' essential functions," are contradictory. The New York Times reports that some lower courts have concluded that "because someone who has applied for or received Social Security disability benefits is by definition unfit for employment, such a person is either barred from suing for disability discrimination or faces special judicial hurdles in pursuing a disability lawsuit." Lambda Legal Defense Fund Legal Director Beatrice Dohrn said the Supreme Court's decision "could be particularly beneficial to people" with HIV since they often "move in and out of being able to work" and frequently encounter discrimination when they do work. She said the decision "broke down a barrier that people with HIV needed to get past" (Greenhouse, New York Times, 5/24).

- *American Healthline*

05-24-1999

POLITICS & POLICY - MEDICAL MARIJUANA: ADMIN. EASES AVAILABILITY FOR RESEARCH

The Clinton administration Friday announced that it will sell government-grown marijuana to scientists who want to study the drug. The Los Angeles Times reports that for most of the last 20 years, "the production and distribution of marijuana for clinical research has been restricted under several federal laws and international agreements, making it all but impossible for non-federally funded researchers to obtain it" (Cimons, Los Angeles Times, 5/21). The New York Times reports that Office of National Drug Control Policy Director Gen. Barry McCaffrey, an "ardent" opponent of medical marijuana, supported the decision. The office's chief counsel, Chuck Blanchard, said that "as long as you are willing to show that it is high-quality research and also provide your own funding, you can have access to medical marijuana." Experts expressed hopes that eased access to the drug could produce alternative delivery systems, such as inhalers, that "enable patients to benefit without suffering the toxic effects of smoke" (Stolberg, New York Times, 5/22). Researchers will submit study proposals to a Public Health Service medical committee for review (Sisk, New York Daily News, 5/22).

Reactions

Medical marijuana and HIV/AIDS advocates hailed the decision. Allen St. Pierre, executive director of the National Organization for Reform of Marijuana Laws Foundation, said, "For the last 22 years, the federal government has had a lock on the use of whole smoked marijuana for studies -- they grow it at the University of Mississippi. ... We've been imploring the government to come up with a system that will allow these studies to go forward. We want to do the science, but marijuana has become so politicized" (Los Angeles Times, 5/21). Still, some charged that the White House's policy shift did not go far enough. Lindesmith Center Director Ethan Nadelmann said, "It is a tiny step forward, but far too tiny. It's an implicit acknowledgment that the government has blocked research into medical marijuana for explicitly political reasons for the last two decades" (New York Times, 5/22).

- *American Healthline*

05-21-1999

POLITICS & POLICY - RICKY RAY: MONEY FOR HIV+ HEMOPHILIACS UNCERTAIN

Spending caps and competing projects may result in less-than-total funding for the Ricky Ray Hemophilia Relief Act, which was passed last year in an effort to provide payments of $100,000 each to the 7,500 hemophiliacs who were infected with HIV via tainted blood transfusions. The funding is expected to be included in the Labor-HHS appropriations bill, but the bill is "facing a reduction of more than $11.5 billion in discretionary funding from last year," CongressDaily/A.M. reports. "Obviously there's no room for existing programs," said John Porter (R-IL), who chairs the House Labor-HHS Appropriations subcommittee. Porter, who emphasized that funding Ricky Ray was a priority, added that with the current funding restrictions, "We probably won't even be able to get the bill through the subcommittee. The prospect of getting [Ricky Ray funding] all done in one year is very daunting, even with a good budget allocation." CongressDaily/A.M. reports that the news has advocates for hemophiliacs outraged. "We're very steamed," said Dave Cavenaugh of the Committee of 10,000, a group representing hemophiliacs with HIV/AIDS. "We're very confident we won't be offered the full amount, and we will be outraged," he said (Rovner, 5/21).

- *American Healthline*

05-21-1999

POLITICS & POLICY - NEEDLE STICKS: REPS. SET TO INTRODUCE SAFE NEEDLE ACT

Backed by the American Nurses Association, Reps. Pete Stark (D-CA) and Marge Roukema (R-NJ) are expected to introduce today a bill that would mandate the use of safe needles, the San Francisco Chronicle reports. At the same time, Labor Secretary Alexis Herman promised yesterday to protect the nearly 1 million health care workers who sustain needle sticks each year, resulting in "thousands of illnesses and hundreds of deaths" via HIV or hepatitis infections. The Occupational Safety and Health Administration is considering a three-pronged approach, Herman said, noting that the agency will require all health care facilities to record needle stick incidents, encourage the use of needles with safety features -- protective sheaths or retractable needles -- and "consider toughening regulations designed to protect health care workers from infected blood." The measure put forth by Stark and Roukema, the Health Care Worker Needlestick and Sharps Injury Health Act, would take the OSHA requirements one step further by requiring employers to use engineered sharps (Sandalow/Holding, 5/21). In addition, the measure would create an injury log and a clearinghouse for information on new safe-needle technologies; and require employers to provide training to health care workers. Sen. Harry Reid (D-NV) is expected to introduce similar legislation in the Senate.

"It is unconscionable that there are safely devices available, yet they're not being provided to health care workers," said ANA President Beverly Malone (ANA release, 5/20). Nurses unions estimate that the regulations will cost $700,000 annually for a 300-bed hospital, which they say is far less than the cost of testing and treatment for health care workers inadvertently stuck with unsafe needles. Stark, who modeled the bill on California's safe-needle law, dismissed the financial costs of enacting the legislation, saying, "This is not something that the budget bean counters here would waste any time on" (Chronicle, 5/21). See the Kaiser Daily HIV/AIDS Report for additional HIV/AIDS coverage.

- *American Healthline*

No Date Provided

HEALTH - Approps Hurdles High For Tainted Blood Compensation

Advocates pressing for compensation for the estimated 7,500 hemophiliacs who contracted the AIDS virus from contaminated blood clotting factors in the early 1980s thought the hardest part of their job was over last year, when Congress passed the Ricky Ray Hemophilia Relief Act on the final day of the session.

Now, faced with the hurdle of getting $750 million for payments of $100,000 each actually appropriated, they are thinking again.

"We're very steamed," said Dave Cavenaugh of the Committee of 10,000, which represents hemophiliacs with HIV/AIDS, after the group was rebuffed in its efforts to have the funding included in the supplemental appropriations bill cleared by the Senate Thursday.

He added: "There is no ethical way to make these families wait anymore after waiting for 13 years. Some of these patients won't even be around."

Getting the payments funded as part of the regular appropriations process also will not be an easy task. The funds would have to be part of the Labor-HHS appropriations bill, which is facing a reduction of more than $11.5 billion in discretionary funding from last year.

Then, Republicans will have to make good on promises to increase substantially funding for the National Institutes of Health, thus drawing even more from other programs in the bill.

Faced with those circumstances, said House Labor-HHS Appropriations Subcommittee Chairman John Edward Porter, R-Ill., funding the Ricky Ray bill will be an uphill battle.

"Obviously there's no room for existing programs," Porter said in an interview, much less new ones. With the current allocations, "We probably won't even be able to get the bill through the subcommittee," he said.

While funding the Ricky Ray payments is "a high priority," Porter said, he warned that the hemophilia community should be prepared to get less than the full amount.

"The prospect of getting it all done in one year is very daunting, even with a good budget allocation," he said.

Cavenaugh said his forces are prepared for that eventuality, and will fight it. "We're very confident we won't be offered the full amount, and we will be outraged," he said.

- *CongressDailyAM*

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Book Review

Latino Gay Men and HIV

Latino Gay Men and HIV. Rafael M. Diaz, Routledge, New York, 192 pp., $17.99.

> Ten years into the AIDS epidemic, with full public awareness that HIV infection is running rampant among gay men of color, empirical studies of Latino gay men could be counted with the fingers on one hand. Rafael Diaz, Summer 1992

Although Latinos represent a rapidly growing proportion of new HIV infections and AIDS diagnoses in the United States, few epidemiological and behavioral studies explore the reasons why Latinos have increasingly higher rates of transmission than non-Latino Whites. The HIV/AIDS literature has, for the most part, been inundated with descriptive and causal reports on American and European gay White men, intravenous drug users, and heterosexual transmission. Unfortunately, interventions based on the results of these studies, which may not be very generalizable, are being applied broadly to other ethnic, racial, and gender groups that have different cultural, socioeconomic, political, and behavioral issues. It is insufficient to think that values, attitudes, and needs are similar among all gay men, regardless of ethnic or cultural backgrounds. While using general labels has been useful in gaining a better understanding of underlying risk factors for HIV infection, such labels stop short of fully identifying why different groups of people continue to participate in risky behavior, even when they know they are putting themselves at risk that can be reduced! Accordingly, it is important for community-based researchers and academicians to go beyond lumping groups of people and then making gross generalizations about what is occurring at the individual or community level. More culturally sensitive research is needed.

Diaz has successfully exposed these misperceptions about using general labels, and he articulately explains why Latino gay men, in particular, do not respond as well as the mostly White gay male community to public health messages regarding risk reduction; he calls this a "deficit" pedagogy. Diaz' argument for the purpose of his book is the following: "We must critically examine the teaching styles or pedagogy underlying our AIDS prevention and education activities, especially when those activities are directed to minority populations and, in particular, Latino gay men."

Diaz' approach throughout the book is honest, direct (sometimes uncomfortably so), and bridges two worlds which are mostly disconnected, the academic and mostly theoretical one and the community-based and very applied one. I found his directness refreshing, as most articles and books we read about HIV transmission camouflage reality with academic jargon or sometimes prudish analyses—and, therefore, interpretations or implications are lost or misdirected. For example, Diaz discusses risky sex as a natural and meaningful behavior, and he states, "the powerful and deeply satisfying experience of semen exchange between two men . . . is definitely out of the question with condom use under the threat of HIV transmission. . . . *Al pan pan y al vino vino* (call bread bread and wine wine, . . . that is, truth must be told even if difficult consequences must be faced)."

What is sometimes lost to HIV/AIDS researchers and community workers is that Latino gay men are strikingly different than their White and Black counterparts. Diaz explicitly states that many Latino gay men are caught in (1) social isolation between the homophobia of their families and native communities, and (2) the racism of the mainstream gay community. These two factors along with issues of acculturation, nationality, class, and migration make HIV prevention for Latinos complex and challenging. Many people are deep "in the closet" about the very real and deeply seated racial and ethnic divisiveness that exists in the gay and lesbian communities. It should be understood that many gay men and women of color do not have the same social access and community support that is afforded to White gays and lesbians, and that alone makes HIV prevention and outreach difficult, particularly for Latino gay men.

Diaz' training in developmental psychology and social work proves useful in his analyses and interpretations. His overall hypothesis is that six sociocultural factors in the lives of Latino gay men—machismo, homophobia, family loyalty, sexual silence, poverty, and racism—undermine the self-regulation of sexual-

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ity and are barriers to practicing safe sex. In his Introduction, Diaz offers four contributions:

1. A thorough and critical review of the existing literature
2. A cultural model of HIV risk, based on the voices and subjective experiences of Latino gay men
3. A "psycho-cultural" model of sexual regulation
4. The results of an HIV-prevention intervention targeted to Latino gay men that addresses the cultural barriers to safer sex and promotes sexual self-regulation in a culturally sensitive fashion

THE EXISTING LITERATURE

Given that Diaz had little literature with which to work, the review of the epidemiological and behavioral literature is informative. Diaz focuses on four epidemiological studies of Latino gay and bisexual men. As expected, Diaz reports that Latino gay men have higher *rates* of HIV infection and are at higher *risk* of infection than non-Latino Whites (with one study in Chicago finding that Latinos have 330% higher risk than White gay men). He also finds that among Latino gay men there is an aversion toward using condoms, and he offers several explanations as to why. Overall, the literature review is informative and awakening.

A CULTURAL MODEL OF HIV RISK

Diaz' goal is to examine why many Latino gay men practice unsafe sex and continue to put themselves at risk when they intend not to and when they know how to prevent such risk. He describes the psycho-cultural model to explain this phenomenon. The psycho-cultural model is in contrast to the social-cognitive models in that "individuals' behaviors will be guided and regulated by internalized cultural factors, that is, cultural guidelines of behavior that are highly over-learned, routinized, scripted, and automized." Diaz hypothesizes that Latino gay men practice unsafe sex in light of knowledge and intention to practice safe sex because individuals' behavioral intentions are determined by cultural factors or scripts. Three assumptions underlie the psycho-cultural model: (1) sociocultural factors are internalized as cognitive scripts that guide and give personal meaning to sexual behavior; (2) individuals can practice health-promoting behaviors even if those behaviors are at odds with cultural scripts, but these safer practices depend on the individual's intentions, capacity to exercise self-regulation, self-determination, and level of support; and (3) in case of a volitional breakdown, cultural, cognitive, and sexual scripts, instead of personal intentions to practice safe sex, will be the main regulators and determinants of behaviors.

HERMANOS DE LUNA Y SOL: A MODEL FOR HIV PREVENTION WITH LATINO GAY MEN

Diaz discusses an intervention called Hermanos de Luna y Sol (HLS), which he helped implement. HLA was implemented in San Francisco's Mission District and targeted mostly immigrant, Spanish-speaking gay men of low socioeconomic status. He states that the intervention was guided by the integration of three conceptual frames: (1) Bandura's theory of self-regulation; (2) principles of empowerment education; and (3) the psycho-cultural model of HIV risk. He discusses the intervention components including bar outreach, recruitment activities, the survey, a culturally sensitive outreach card, and the group intervention. Diaz reports the evaluation of the implementation and clients' perceptions of the effects of the intervention. While HLS is an on-going intervention and has yet to be evaluated on different aspects of the intervention such as the effectiveness of the program to reduce HIV risky behavior and its sequelae, and despite some problems with follow-up and retention, the results presented support that HLS is a success in the perceptions of the clients. The participants were likely to say that the intervention was helpful in reaffirming their intentions to practice safer sex and increasing their self-efficacy to practice safer sex. Additionally, the participants were likely to agree that the program made them feel connected to the Latino gay community. I look forward to hearing about the program's evaluation after the printing of the book. It appears that HLS is promising.

CONCLUSION

In short, *Latino Gay Men and HIV* is an intelligent and well-written book—it is a major contribution to the HIV disease prevention literature. Additionally, it adds to the general literature on race, ethnicity, and disease. Any HIV/AIDS researcher, activist, or provider will find this book accessible and useful, and I should add: important! I will be recommending this book to my students and colleagues for years to come. Diaz has produced an excellent piece of scholarship.

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Journey to the epicenter of AIDS

SOWETO, South Africa - When the AIDS virus detonates in this black township of 3 million in a decade or so, the disease will wipe out about 600,000 souls - almost six times as many people as the atomic bombs killed in Hiroshima and Nagasaki. But unlike a nuclear blast or world war, the AIDS crisis is an explosion in slow motion, a creeping chain reaction with no end in sight. There is no sound, no searing heat, no mushroom cloud, no buildings reduced to rubble. Just one mute death after another. Sandra Thurman has come here to break that silence. Director of President Clinton's Office of National AIDS Policy, Thurman hopes to bring home to the American people and to Clinton the immensity of the crisis in South Africa. To this end, Thurman and a team of U.S. officials recently traveled through South Africa, Zambia, Zimbabwe and Uganda. A USA TODAY reporter and photographer accompanied them to document the ravages of what is now the No. 1 cause of death in Africa.

Time bomb ticks south of Sahara
By Steve Sternberg, USA TODAY

SOWETO, South Africa - When the AIDS virus detonates in this black township of 3 million in a decade or so, the disease will wipe out about 600,000 souls - almost six times as many people as the atomic bombs killed in Hiroshima and Nagasaki.

But unlike a nuclear blast or world war, the AIDS crisis is an explosion in slow motion, a creeping chain reaction with no end in sight. There is no sound, no searing heat, no mushroom cloud, no buildings reduced to rubble. Just one mute death after another.

Sandra Thurman has come here -- to the country where AIDS is spreading faster than in any other on Earth - to break that silence.

Director of President Clinton's Office of National AIDS Policy, Thurman hopes to bring home to the American people and to Clinton the immensity of the crisis in South Africa and the other countries south of the Sahara that form the epicenter of AIDS.

To this end, Thurman and a small team of U.S. officials recently traveled through South Africa and three other countries at the heart of Africa's AIDS epidemic: Zambia, Zimbabwe and Uganda. A USA TODAY reporter and photographer accompanied them to document the ravages of what is now the No. 1 cause of death in Africa.

In all, 11.5 million people have died in sub-Saharan Africa since the epidemic emerged in the early 1980s, and 22.5 million now living with the virus are expected to die in the next 10 years, according to UNAIDS, the United Nations' AIDS agency.

Staggering as the numbers are, Thurman believes that the sub-Saharan epidemic has been met with indifference by Americans and, to some extent, by their government, which spends $74 million a year on AIDS programs in the region. In contrast, Congress this month voted to spend $1.1 billion to assist roughly 750,000 Kosovo refugees.

"When you're looking at whole generations of adults and children in jeopardy - we ought to be able to hold hands and sing Kumbaya around that," Thurman says. "We can't do anything if we can't do this."

To gauge the social and political costs of AIDS here, Thurman visited cities and shantytowns, orphanages and hospitals, taking in scenes from an epidemic.

One of Thurman's first stops was at the Javabu clinic, headquarters of the Soweto Project - an effort to unite medical care, social support and AIDS prevention.

The project is the brainchild of Mark Ottenweller, 10 years ago a prosperous internist in a leafy suburb of Atlanta. Today, at 47, he works in Johannesburg as a medical director of Hope Worldwide, the relief arm of the International Church of Christ.

The clinic is housed in a small cluster of brick buildings on a broad lawn, bordered by brilliant splashes of jacaranda and bougainvillea. To its beneficiaries, it's a lifeline.

Mary Mudzingwa, 35, mother of Chipo, 9, and Gift, 5, credits the Soweto for helping her adapt to life with HIV. "I lost my job. I lost a place to stay. Now I stay with friends, but there's no toilet, no water. Maybe that's why my 9-year-old is always sick." She says that one of the most difficult things about having the virus is the way it changes how people respond to you. "Some people, I told them I am HIV-positive. They were afraid. I said, 'Don't be afraid. We look like other people.' "

Many of the people Mudzingwa was preaching to

probably are infected themselves, though they don't know it. Ninety-five percent of HIV carriers in sub-Saharan Africa have not been tested because tests are in short supply and many people deny they are at risk. Consider the men Ottenweller comes across a few days later, on an AIDS-prevention foray into the shantytown of Klipstown, near Soweto. They grow silent as Ottenweller approaches. "I'm Dr. Mark," he says, half in Zulu, half in English. "How many of you guys wear condoms?" Quizzical smiles bloom on embarrassed faces. Half the men raise their hands; half seem indifferent. "I never use a condom," one man says defiantly. "I stick to one partner." "But does she stick to you?" the doctor asks. "Come see me at the clinic when you get sick." "Ten years from now, one-fifth of these people will be dead," Ottenweller says later. "HIV is going to hit this place like an atom bomb."

Tests of women in prenatal clinics, a group believed to reflect the infection rate in the general population, show that at least one of every five people in South Africa, Zimbabwe, Zambia and Botswana is infected with the AIDS virus. That means those nations stand to lose at least one-fifth of their populations, a death toll that rivals the Black Plague in medieval Europe.

In some places, the infection rates are much higher. In South Africa, between 1991 and 1997, the infection rate on average soared from 2% to almost 18%. And in South Africa's most populous province, KwaZulu-Natal, the rate has reached 37%.

Alan Paton, in the classic 1948 novel Cry, the Beloved Country, described the province's rolling green hills as "lovely beyond any singing of it." Those lovely jade hills outside Pietermaritzburg are still there. But there also stands a massive brick building that is overflowing withhuman misery beyond any lamenting of it. The building is a hospital known as Edendale. During apartheid, it was for blacks only. That soon will change, as part of a massive South African health reform program under way. For now, the battered wooden benches lined up in corridors and the large anterooms in the hospital's wards are packed with black people. Some are waiting to deliver babies - 8,000 are born here each year, although there is just one obstetrician on the staff.

On average, 20 children are admitted to Edendale each day. More than 60% are infected with the AIDS virus, says pediatrician Johnny Ahrens, and they often are brought in by their grandmothers or aunts because their mothers have died. The nurses in the pediatric HIV ward, once accustomed to returning children to health, now are so overwhelmed with dying infants that they are on the brink of cynicism.

Many nurses, Ahrens says, are beginning to think: "If there's nothing you can do to help, why bother? It's just one more dying child." Ahrens himself is furious because he thinks the government should have done something, anything, to stop HIV before it took hold. "We all knew that HIV was going to hit South Africa. It was coming down through Africa like a red tide. People were trying to warn us. But nothing ever happened."

Baby's touch pushed chief to front-line fight
By Steve Sternberg, USA TODAY

WASHINGTON -- Unlikely as it may seem, cuddling an abandoned, HIV-positive baby in Atlanta's Grady Memorial Hospital almost two decades ago set Sandra Thurman on the road to the White House.

Thurman, 46, is director of President Clinton's Office of National AIDS. But as someone raised in the maelstrom of Southern politics, she initially set quite a different course for herself. Her father was a businessman, her mother one of Atlanta's first female lawyers - the late, liberal chairwoman of Georgia's Democratic Party. Thurman learned politics from the rough-and-tumble members of the state legislature.

To achieve her goal of helping people, however, she took a more hands-on approach, studying counseling at Mercer University's Atlanta campus and working with imprisoned youthful offenders. After caring for her dying father at home, she took a course in hospice care and became a hospice volunteer. Then, at the suggestion of a friend, Thurman agreed to visit an HIV-positive baby at Grady Memorial. "It was a life-altering experience," she says. "To go to a hospital like Grady and care for a child who was clearly dying and had been abandoned really helped me understand what abandonment meant. Not only for this child, but for adults who had HIV and were abandoned by their families because they were gay or for any other reason." In 1988, Thurman decided to plunge full time into the battle against AIDS. She applied for a job running a nonprofit agency called AID Atlanta, which provided a safety net for thousands of AIDS sufferers. Five years later, seeking a new challenge, she accepted a post as director of child advocacy for the Carter Center Task Force for Child Survival.

But the respite from AIDS was temporary. Her work on Clinton's 1992 and 1996 campaigns earned Thurman her 1997 appointment as Clinton's AIDS czar. Officially the

nation's No. 1 AIDS fighter, she must contend with a minimal budget, few paid staffers and responsibility for coordinating the government's extensive but fragmented AIDS programs.

The task, Thurman says, was made tougher by sparring over budgets, turf and approaches to public health. In her view, this was only one reason why the U.S. government has moved slowly on AIDS. Another was a lack of leadership. "By the time an American president mentioned the word AIDS, there were 30,000 dead," she says. Acting on the same impulse that drew her to social work, Thurman decided to use her pulpit to attack AIDS worldwide. Her first priority: African children. "Children can't speak for themselves," she says. "They are the least of the least in this epidemic, and they are getting hit the hardest."

The global AIDS epidemic will have such a profound impact on families that Thurman believes it will become a bipartisan issue. The challenge, she says, is getting Congress to fund an aggressive prevention effort. That's why Thurman organized a trip to four African countries in February and a second, shorter trip with a congressional delegation in March. "If we can get Republicans and Democrats to agree on anything, we should be able to get them to agree on . . . caring for families, children and orphans," she says.

Sex, separation help HIV hitch ride

MTUBATUBA, South Africa - Gugu Zulu, 22, lives in a world of women, children and old men. The young men, desperate for work, have disappeared into the steamy depths of South Africa's mines. Gugu Zulu's 25-year-old boyfriend is one of 600 young men from this district in the heart of Zulu country who work about 400 miles away, near Johannesburg, in the Carletonville gold mine. They are the muscle and blood driving South Africa's century-old migrant labor system -- one of the more stubbornly persistent fuels spreading the brush fire of AIDS throughout southern Africa. Though Gugu Zulu would like to marry and have a family, she has a tough time envisioning the future with a man who returns home for visits that total just eight days a year.

All told, nearly 500,000 women share her plight, studies show. At least 88,000 South African men and 300,000 men from neighboring Botswana, Zimbabwe, Namibia, Mozambique, Lesotho and Swaziland are migrant workers in South Africa's mines and other industries. Many of the men live in barracks-style, single-sex hostels, often crammed beyond capacity.

After work, many men drop into taverns and hook up with willing women, many of whom are prostitutes infected with HIV. An estimated 400 prostitutes work in Carletonville, lured by the gold miners' wages.

Many of the miners regard HIV as a distant risk, a viewpoint perhaps understandable because their jobs pose an even bigger risk. The average gold miner stands a 1-in-40 chance of getting crushed by a mine shaft cave-in, according to a study by the South African government. Given that risk, HIV may seem like a minor concern. But the disease is spreading faster here than anywhere else in the world.

The AIDS virus has infected one in 16 South Africans, an estimated 2.9 million people, says UNAIDS, the United Nations' AIDS program. More than 700,000 people were infected in 1997 alone, UNAIDS says. Tests of pregnant women indicate that the KwaZulu-Natal province, with population of migrant workers, has the heaviest concentration of HIV infections in South Africa. "It doesn't take a rocket scientist to figure out that if you want to create a sexually transmitted epidemic, you would find as many young, rural men as you could, move them into an urban area, house them in single-sex hostels and give them easy access to commercial sex and alcohol," says Mark Lurie of the Johns Hopkins University School of Public Health in Baltimore. And if you want to spread the disease to rural districts, he says, you would send the men home again.

Migrant laborers first were employed throughout sub-Saharan Africa by colonists seeking to extract the region's mineral riches from mines near predominantly white cities. South Africa formalized this trend by creating a nationwide system of pass laws. The government offered African workers passes that permitted them to travel between their homes and mines but barred them from settling down with their families near the white-dominated cities where they worked. Under this system, men typically worked in the cities, leaving their wives in rural areas. If they got too sick to work, they were fired and forced to return home.

Paradoxically, the relaxation of South African pass laws in the mid-1980s appears to have accelerated the spread of HIV by eliminating travel restrictions, researchers say. Studies in eastern Africa have shown that truckers, their mechanics and the assistants who traveled with them along the Trans-Africa Highway helped spread HIV throughout that region. Studies conducted between 1989 and 1992 found the highest infection rate, 30%, among people living near trading centers along the

highway. A survey of bus and truck drivers in Cameroon found that 68% of the drivers had extramarital sex during their last trip, and 25% had sex every night they were away, according to a report by the nonprofit public health group Family Health International. The average trip lasts 14 days.

Lurie, backed by the Wellcome Trust in London, plans to dissect the links between labor migration and HIV in the heart of South Africa's Zulu region. Although his study is just getting under way, Lurie says the evidence already suggests that men aren't the only ones who are helping to spread HIV. The evidence comes from a study of men who migrate to work and their home-bound sex partners. Of the first 31 couples enrolled in this study, Lurie has found, 11 couples are discordant, meaning that just one partner is HIV-positive. In six of those couples, the male is positive, indicating that the men brought HIV home.

But there are five couples in which the woman is positive and the man is negative, Lurie says. This suggests that prolonged separation prompts women to seek out other sexual partners. When Gugu Zulu questions her boyfriend about life in Carletonville, heconcedes that he sometimes takes other lovers. "I'm a man," he tells her. But he insists that his other liaisons are simply a tonic to his daily ordeal of danger, fatigue and loneliness. Although she says she doesn't like this situation, there's not much Gugu Zulu can do. She says she has been tempted to sleep with other partners, increasing her risk. Neither her boyfriend nor other potential partners will use condoms, she says. "If they won't use condoms with me, they won't use condoms with anyone else," she says. "Can you tell someone has HIV by looking at them?"

Victims lost in battle over drug patents
By Steve Sternberg, USA TODAY

JOHANNESBURG, South Africa - For two years, the United States and South Africa have been locked in an unpublicized trade war. At stake is access to expensive AIDS drugs, which are as out of reach for most HIV sufferers here as ingots of South African gold.

At the heart of the conflict is a broader problem: the chronic shortage of drugs in poor countries. Although drugs are a simple, potentially low-cost remedy for such developing-nation ills as sleeping sickness, dysentery and tuberculosis, they often are priced beyond the means of most people who need them. The latest additions to the list are HIV drugs, the quest of desperate patients throughout sub-Saharan Africa.

Two years ago, the South African Parliament took what drug companies and the U.S. government consider radical action: It passed legislation, signed into law by President Nelson Mandela, that allows local firms to make, market and sell generic versions of drugs patented by multinational drug companies. The drug companies then would be paid royalties set by the government. The plan provoked a swift rebuke from the United States, which leapt into the fray on behalf of drug companies. The companies contend that South Africa's action strikes at the heart of free-market capitalism and the patent system. If countries are permitted to make generic versions of drugs before the patents expire, their argument goes, companies will lose their incentive to develop lifesaving drugs. "Paying those prices isn't just a problem for poor people; it's a problem for the middle class," South African Health Minister Nkosazana Zuma says. "Even I, on my salary, couldn't afford triple-drug therapy" for HIV.

That the most powerful country in the world would spar with the most promising emerging democracy in Africa over access to AIDS drugs illuminates the daunting variety of challenges that the HIV pandemic presents worldwide. It also shows how fiercely drug companies will fight to protect profits from anti-HIV drugs, a rich market with sales totaling roughly $3 billion a year.

Jeff Truit of the pharmaceutical trade group Pharma says the South African government has refused to negotiate directly with drug companies, which have offered South Africa concessions on most drug prices. Instead, Truit says, the country is mounting "a brazen assault on patent protection, the lifeblood of our industry." But Zuma and many of the world's public health officials regard HIV as an international emergency that should rise above patents.

"Pharmaceutical companies should be sensitive to public health issues," Zuma says. "No one wants them to go under. We're not quarreling with their profits at all. If they would make these drugs available in the Third World, they can make up their losses on volume."
At the crux of the dispute is the South African Medicines Act, which legislators amended in 1997 to permit local manufacturers to make generic versions of AIDS drugs. Within months, the South African pharmaceutical trade group, backed by at least 40 drug companies, challenged the constitutionality of the amendments in court. That put the law on hold until a court decides. Meanwhile, the United States has tried a variety of tactics to get South Africa to withdraw or

amend the 1997 law.

U.S. Trade Representative Charlene Barshevsky has argued that the 1997amendments are so broad that they could be applied to other medicines. In an effort to apply more pressure, she denied South Africa tariff relief on certain exports to the USA.

"There has been subtle and not-so-subtle international pressure on the South African government in regard to this legislation," South African diplomat Peter Goosen told the World Health Organization's executive board in January. "While we remain open to persuasion by rational arguments, our commitment to the principles that underpin our legislation is unwavering." Truit says the South African government's stand threatens the development of medicines. The average drug costs $300 million to $500 million to develop. One company, which Truit declined to name, spent approximately $1 billion to create a single anti-HIV drug, he says.
But those drugs are unavailable to 95% of the world's HIV sufferers, meaning all the money and effort involved in developing drugs for HIV serves just 5% of the people who need them.

Virus makes families pay twice
By Steve Sternberg, USA TODAY

Children, even if they never get HIV themselves, are poised to become helpless victims of the virus's march through sub-Saharan Africa. Over the next decade, the deaths of millions of parents will leave tens of millions of orphans to fend for themselves on the streets and in the countryside. Few families will escape.

One-fourth of the children in sub-Saharan Africa live in a family in which an adult is HIV-positive and in need of medical care, according to UNAIDS, the United Nations' AIDS organization.

"Children are the first to know a parent is sick. Often, parents won't admit it to themselves, much less to anyone else," says John Williamson, the author of a landmark study, Children on the Brink, and a consultant to the U.S. Agency for International Development (USAID). In sub-Saharan Africa, 40% of children are stunted by malnutrition. A parent's HIV infection puts the child in even greater jeopardy. As soon as a parent becomes ill, a child's school attendance drops because parents can't afford school fees, books and uniforms, or they need the child's labor to help feed the family and pay medical bills.

No one knows how many "child-headed" households are in Africa, though the clues are deeply disheartening. For example, studies show that in the Rakai district of Uganda, the heart of Africa's AIDS epidemic, 4% of the households are headed by children. And the AIDS epidemic in sub-Saharan Africa is just gathering steam. In nine countries, 20% to 33% of children will be orphaned over the next decade as the death toll climbs. All told, UNAIDS expects 40 million children to be orphaned in coming years, a population equivalent to all the children living in the USA east of the Mississippi. Says Williamson: "We haven't seen anything yet."

Zambia: The cradle of Africa's crisis
LUSAKA, Zambia - Fountain of Hope resembles nothing so much as a refugee camp for children. And it is nearly that for 1,500 of the 128,000 orphans who live on the streets of this lush capital, with its broad boulevards and spreading trees.

This informal day school in a shabby recreation center downtown was the first stop outside South Africa for Sandra Thurman, the White House's top AIDS official, on a recent fact-finding mission to see the AIDS crisis in Africa. Each morning, the youngest victims of AIDS, ranging in age from 3 to 15, straggle in from the streets. They don't come for the books or the playground or the toys. There aren't any. And there's nothing distinctive about the rec center, built of unadorned concrete. They come because it's better to be here than in the lonely streets, where food is scarce and companionship often involves sex with an older child. Here, volunteers teach reading, arithmetic and music. And there's food -though only every other day.

Zambia once was one of the richest countries in sub-Saharan Africa. It supplied copper for the bullets the United States used during the Vietnam War. Now this country of 11.5 million is one of the poorest - and bears the distinction of having one of Africa's largest orphan populations. In 1990, Zambia had roughly 20,000 orphans. By next year, says UNAIDS, the United Nations' AIDS organization, there will be 500,000. "The numbers of orphans are increasing by the day," Zambian President Frederick Chiluba tells Thurman. "Street kids are everywhere, and we don't have the funding to care for them."

And they're not just concentrated in the cities. For example, the shantytowns called St. Anthony's and Mulenga's compounds, in Kitwe near the Congolese border 150 miles from Lusaka, have huge numbers of orphans - about 20% of each town's 10,000 residents. Eventually, many orphans find their way here to Lusaka.

In 1996, when the Fountain of Hope school started, there were 50 children, outreach coordinator Goodson Mamutende says. Just three years later, 30 times that many attend classes in two shifts. Fountain of Hope staffers estimate that half the children have been abandoned; the other half have lost parents to HIV. And with 700 HIV-related deaths each week in Lusaka alone -- a number so large it has caused weekend traffic jams and day-long waits in the cemeteries - the number of orphans and abandoned children continues to multiply.

Dirty-faced, wearing the cast-off clothes that are their only possessions, the children eagerly cluster around a makeshift blackboard to learn arithmetic and the alphabet. They learn to sing in unison, acting out the songs enthusiastically. "Fight child labor with an AK-47," they shout, thrusting their arms as if they were firing guns. Nicholas Mwila, 23, who has written the words for many of their songs, is the art director. "I take them as they are, the way I find them," he says. "I want them to dress as they do on the street. I don't encourage them to take a bath."

These "gutter kids," Mwila says, project a message to Thurman and the visiting foreigners: "The problem is real." After school, when they return to the streets, the children beg, steal and, in many cases, sell sexual favors for food. At night, they sleep in culverts along a thoroughfare called Cairo Road. Most prized, especially in winter, are the culverts across from a gas station. On cold nights, volunteers say, the children fight the chill by getting high on gasoline fumes or on methane inhaled from bottled, fermented excrement.

Jack Phiri, 14, traveled 150 miles to Lusaka from Ndola, in the copper belt, where statistics show that 46% of young pregnant women are infected with HIV. Jack says his mother died in 1996 of tuberculosis - the leading killer of people with AIDS in Africa. He says he doesn't know what killed his father; staffers at Fountain of Hope are convinced the culprit was HIV.

Fiddling with the ragged edges of his cut-off jeans, Jack says he has lived on the streets since 1997. His brother has been taken in by relatives and has vanished from Jack's life. The "auntie" who took Jack refused to feed him and made him sleep outside her hut. So he stowed away aboard a train and ended up here. The other kids in the street told him about Fountain of Hope. "I like being here because I can go to the school," he says. "And they give you food." Asked whether he remembers what it's like to have a family, Jack's eyes flood with tears. "He cries very easily," Fountain of Hope staffer Rogers Mwewa says. "He hasn't developed the survival skills of most of the other kids."

When he grows up, will he have a big family? "I don't know if I'll live that long," Jack says. Jack spends most of his nights sleeping near fast-food restaurants on Cairo Road. After dark, children clog the sidewalks, chasing anyone who might be persuaded to part with money for food.

One night recently, staffers from Fountain of Hope and an official from the Dutch Embassy dug into their pockets for money to feed 78 starving children. Buoyed by the prospect of a meal, the children waited patiently on the sidewalk while an older child counted them. Tomorrow night, they knew, they might not be so lucky.

Zimbabwe: Kids forced into manhood
By Steve Sternberg, USA TODAY

MUTARE, Zimbabwe - At 15, Willard Tinet is the man of his house, single-handedly caring for brothers Joseph, 14, and Cloud, 12. The boys' mother died of AIDS, but Willard doesn't know when. "She died a long time ago," he says sadly. The boys' father disappeared after his wife became ill. An older sister married and moved in with her husband's family, abandoning her brothers. A community volunteer, Maris Kazewbe, believes that the boys have been living alone since 1994.

But the Tinet children are luckier than some orphaned by AIDS; they have a place to lay their heads. Thousands of others live on the streets. For Willard, today is special because he is receiving an eminent guest in his home: Sandra Thurman, the White House's top AIDS official. It is Thurman's third stop on her mission to four sub-Saharan countries devastated by AIDS.

Clad in rags, Willard sits cross-legged on the floor of the family's tiny, boxlike concrete home. It is on the outskirts of Mutare, in the mountainous western highlands that border Mozambique.
The walls of the one-room cell are pale green, now chipped and stained. There are a few sticks of furniture and a filthy, mirrored armoire, a relic of happier times. Willard seems quiet, almost unaccustomed to speech. But at times the personality of an ordinary 15-year-old penetrates the awkwardness and silence. "How do you eat?" asks Thurman, sitting next to Willard on the concrete floor. "I prepare the meals," Willard answers through United Methodist Bishop Christopher Jokomo, whose grandfatherly appearance seems to reassure the boy.

Willard says he and his brothers grow some vegetables in the community garden. If all fails, they go to bed hungry. They also get weekly visits from Maris Kazewbe and Elizabeth Chihota, volunteers from the Family AIDS Caring Trust (FACT) site at the St. Augustine mission in Mutare. "Sometimes I am here late in the day and there's nothing, no food," says Kazewbe, who then goes out and gets the boys something to eat. St. Augustine, one of the parishes over which Jokomo presides, is one of five FACT sites. All told, 137 FACT volunteers care for 4,000 orphans, from infants through 15-year-olds.

In this country of 12 million people, where one of every three sexually active adults is believed to be infected by HIV, the problem is certain to grow. UNAIDS, the United Nations' AIDS organization, estimates that one-third of the children here will lose one or both parents during the next decade. "Everybody in Zimbabwe has lost someone, either from their immediate or their extended family," says Shadreck Kagora, a pastor and coordinator of Families, Orphans and Children Under Stress, an offshoot of FACT.

Today, Kagora says, most of the nation's nearly 600,000 orphans live with grandparents or other relatives. But family circumstances and cultural barriers strand many orphans in a nether world of hunger, loneliness and neglect. For instance, Willard and his brothers are prisoners of their mothers' belongings, gathered in a small wicker basket suspended from the ceiling. When the boys' mother became ill, relatives from Mozambique came to get her, Chihota explains. "They took her to Mozambique to get well," she says. "They didn't believe she had AIDS." When the boys' mother died, her family failed to come back, collect her belongings and divvy them up among relatives, as Shona tribal custom dictates they should. Until they do, the boys will remain pariahs, shunned by those who would otherwise care for them. Relatives on their father's side of the family, for example, won't enter the until that ritual is completed, to avoid offending the Ngozi, or avenging spirits.

"Instead, the children suffer," Jokomo says.

As Chihota tells the story, Cloud bursts into the house. He stops short at the door, startled to see visitors. He barely speaks; he never smiles. When his apprehension wanes, Cloud's face becomes a mask of emotional desolation. Willard, when asked what he would like to be when he grows up, answers promptly, "A pilot."

Cloud sits on a chair, alone in a room full of people, saying nothing. He seems unable even to contemplate his future. Gently prodded by Jokomo, he mutters: "I don't know." "That little brother there," says Chihota, out of earshot, "what a lot of sadness in his face. Lord, have mercy."

Uganda: Deadly traditions persist
By Steve Sternberg, USA TODAY

KAMPALA, Uganda - Tom Kityo, the tall, animated manager of the AIDS Service Organization, stands before a map of his country, gesturing to one area after another, railing about the traditions that spread HIV. "Here," Kityo says, "the groom's father can have sex with the bride, and that's accepted. Here, other clan members may have sex with someone's wife, and no one says anything." Kityo blames these and other cultural practices for much of Uganda's AIDS problem. It's a situation that, while showing great improvement, still is marking this country with tragic consequences.

A year ago, U.S. officials estimated that 10% of Uganda's 20 millionpeople are HIV-positive - with 67,000 of those infected younger than 15. Nearly 2 million people have died nationwide since what some call "slim disease" emerged here in 1982, leaving thousands of orphans. Government statistics suggest that 600,000 children have lost one parent - and that 250,000 have lost both parents - to AIDS. "We are fighting a lot of complex problems," Kityo says. "There are wars, cultural beliefs, a gender imbalance - these are very difficult things to change." But change is under way in Uganda, which has done more than almost any other country in the world to slow the spread of HIV.

The evidence lies no farther away than a palm-shaded hilltop above the crush of populous Kampala, inside a sprawling white stucco compound enclosed by a tall white wall. Once it was part of the palace of the Bagandan king, now a largely ceremonial figure whose domain straddles the equator and borders the legendary source of the Nile. Today it serves a vastly different purpose. Known as the Joint Clinical Research Center, it is the site of the first HIV vaccine trial in Africa.

On Feb. 8, a nurse guided the first hypodermic into a volunteer's arm -- the first of 40 in the trial. The man, whose name was withheld to protect his privacy, isn't just anybody.

He is a medical orderly on the staff of Ugandan President Yoweri Museveni, the most outspoken of the world's leaders on the threat posed by HIV. Museveni's AIDS awakening came in 1986. Soon after he seized

power from dictator Milton Obote, Museveni got a call from Cuban military authorities who were training Ugandan troops. They told him that 25% of the men had HIV. For Museveni, fresh from a civil war, the news was alarming. An army hobbled by disease can't fight, and Museveni had yet to consolidate his power. By the end of 1986, he had established the nation's first AIDS Control Program. Museveni also issued an international call for help from AIDS researchers and public health organizations. And he declared his intention that Uganda play a key role in any African AIDS vaccine trials. Five years ago, Museveni's prevention efforts began to pay off. Behavior surveys showed that Ugandans were reporting fewer casual sex partners, more frequent condom use and longer delays before young people became sexually active.

More recent studies of pregnant women demonstrate that infection rates have begun to drop. In Kampala, the infection rate among 15- to 19-year-old women fell to 8% in 1997 from 26% in 1992. But traditional practices still exact a steep toll. Indeed, they cost Justine Namuli her life.

Today, in a small family graveyard in a village two hours from Kampala, she will be laid to rest. Hillary Rodham Clinton met Namuli, then 25, two years ago while visiting Uganda. During the visit, Clinton planted a tree to commemorate the opening of the AIDS Information Center's headquarters. There, Elizabeth Marum, a former director of the information and HIV testing center, introduced Namuli to Clinton and Ugandan first lady Janet Museveni. "Justine was sobeautiful," Marum says. "And so excited to meet Mrs. Clinton." Clinton and Museveni listened as Namuli told her life story. In Bagandan tradition, Namuli said, she was "heir to her aunt," meaning she was to take her aunt's place if anything happened to her.

When her aunt died of tuberculosis, Namuli was forced to drop out of school, marry her uncle and care for his children. She was 16. At the time, she didn't know that her aunt was infected with HIV or that her uncle was infected, too. Eventually, Namuli's husband died, but not before he infected her. She, in turn, unwittingly infected one of her two sons.

Namuli quickly sought an HIV test at the information center. Learning that she was infected, she joined the Post-Test Club, a support group that emphasizes safe sex, good nutrition and "living positively." And she joined the Philly Lutaya Initiative, an AIDS education and prevention programnamed for a local rock star who acknowledged publicly he was HIV-positive - the Magic Johnson of Uganda. Like others in the group, Namuli spoke out about HIV and how to guard against infection. "Imagine what this girl has gone through," Marum says. "Her mother died of AIDS. Her aunt died of AIDS. Her husband died of AIDS, and for 10 years she lived with the knowledge that she was HIV-positive."

About a dozen information center staffers and volunteers pile into two four-wheel-drive vehicles for the two-hour drive to Namuli's funeral. The little caravan drives down the truck route, the TransAfrica Highway, connecting Mombasa, Kenya, and Kinshasa, in the Democratic Republic of the Congo. The highway, which runs across southern Uganda, has spread AIDS here, too: The truckers carried HIV from one end of the road to the other, stopping regularly for paid sex with women who needed the money to feed themselves or their families. The women infected their boyfriends and husbands, who infected their wives and girlfriends.

Today, the villages along this road are outposts in an AIDS wasteland, almost entirely by grandparents and children. The middle generation lies in village graveyards. One grandmother, Benedete Nakayima , 70, says she has lost 11 of her 12 children to HIV - six daughters and five sons. She now cares for 35 grandchildren with the help of her surviving daughter. At the Namuli funeral, Marum reads a letter from the U.S. first lady, wishing Namuli a speedy recovery.

Sandra Thurman, the Clinton administration's top AIDS official, who is visiting here in her last stop in a tour of four sub-Saharan countries assaulted by AIDS, was to have delivered the letter to Namuli's bedside at Mulago Hospital on Feb. 7. She was too late.

Namuli died of pneumonia two days earlier - because Mulago Hospital lacked a working oxygen compressor that might have helped her through her respiratory crisis. Her two sons, Moses, 5, and Isaac, 7, have joined the ranks of Uganda's orphans.

"We are going to sing a song of thanks that she died in Christ," says the preacher, wearing a black suit in bold defiance of the searing midday sun. He consults a hymnal that has been translated into Lugandan, the Bagandans' native tongue. He leads almost 100 men, women and children in Jesus, I'm Coming. Soon, it is Lucy Mugoda's turn to speak.

Mugoda, one of Namuli's co-workers at the information center, wastes no time on platitudes or prayers. She has a message: HIV holds no respect for tradition; it seeks

simply to perpetuate itself through any means possible. Namuli died, Mugoda says, not because she was promiscuous or willfully engaged in risky behavior, but because she accepted her traditional obligations as "heir to an auntie." "Let her death serve as an example that not all the old traditions are good," Mugoda says.

"This tradition is death."

The National Association of People with AIDS

FAX

Date: 5/24/99

To: Daniel Montoya

From: Cornelius Baker

Page(s): 3 (including cover)

MEMO: Per Kay Hobbs request, a copy of letter to you.

Please contact us immediately if you do not receive a complete facsimile. Thank you.

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AIDSWatch'99

Chairman James Clyburn
Congressional Black Caucus
319 Cannon House Office Building
Washington, DC 20515

May 2, 1999

Dear Chairman Clyburn,

We are African-Americans from throughout the United States who are attending AIDSWatch'99, a national grassroots advocacy effort on behalf of funding for HIV/AIDS programs. As people living with HIV/AIDS, family members, providers of care and prevention services, and community leaders, we know all too well the terrible impact this epidemic continues to have as it grows among black men, women, youth and children.

Last year, the Congressional Black Caucus led the effort to create the historic $156 million initiative addressing the HIV/AIDS emergency in the African-American community. On behalf of African-Americans across the country, please accept and convey our profound and sincere thanks to every member of the Caucus for their leadership and hard work on this vital issue.

That effort was only the beginning of what is needed. These targeted resources must be maintained and increased in order to support specialized programs and build capacity in our communities. We look forward to working with the Caucus and federal agencies to ensure effective implementation of the initiative.

In addition, it is imperative that appropriations levels for all aspects of HIV/AIDS prevention, research, care and services, housing, and substance abuse treatment and prevention be significantly increased. These federal programs, in addition to targeted funding initiatives, are essential to ensuring that adequate services reach all people living with HIV and AIDS. We urge you to support the appropriations levels requested by NORA (National Organizations Responding to AIDS). These increases are absolutely necessary to meet the rapidly growing needs we see in our communities across the country.

Finally, we urge the Caucus to continue to support efforts to increase U.S. attention to the global AIDS epidemic. AIDS is destroying whole generations in many countries in Africa, and continues to have a profound impact in the Caribbean basin. But while the worldwide epidemic grows, U.S. commitment has remained pitifully small. You are in a position to help remedy that situation.

Your leadership is needed to focus American attention and resources on both the domestic and global needs of the HIV/AIDS epidemic. Our community is counting on you.

Sincerely,