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Meeting with Mr. Austin Jones 6/29/94

Stack:	Row:	Section:	Shelf:	Position:
S	66	5	5	2

DAY: WEDNESDAY
DATE: JUNE 29th, 1994
TIME: 4:45pm - 5:30pm

LOCATION: 750

EVENT: MTG - Ms. AUSTIN JONES
NAT'L PARENT - CHILDREN
W/ AIDS

THE WHITE HOUSE

WASHINGTON

July 19, 1994

Austin E. Jones, Ph.D.
President
National Council on HIV Disease
P. O. Box 66966
Phoenix, Arizona 85082

Dear Dr. Jones:

Thank you for coming in to meet with me on June 29 concerning the exciting programs of the National Parents' Council on AIDS. I am delighted that you have taken the lead in helping to reinforce the importance of public education as a means toward AIDS prevention.

HIV prevention is one of the areas this Administration has made a priority. With the focus on prevention planning moving more toward communities, organizations such as yours are vital in making clear what must be done. We must assure that every school in the our country provides its students with HIV/AIDS prevention education and that community organizations reenforce this message. Organizations such as yours can be our best tool.

Carlos Velez, our lead staff person on AIDS Prevention, is available to offer you additional assistance and to help you continue to make the appropriate linkages to assist your organization. Mr. Velez can be reached at (202) 690-6248.

Again, thank you for coming in to see me.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

National Parents' Council on AIDS
P.O. Box 66966
Phoenix, Arizona 85082

FAX COVER SHEET

29 JUN 94
4:45 PM

750

TO: Gus Ventura

Tel.
FAX (202) 632-1096

FROM: Austin Jones
Tel. (602) 994-9028
FAX (602) 945-5590

DATE: June 15, 1994

NO. OF PAGES (INCLUDING COVER) 4

MESSAGE:

National Parents' Council on AIDS
P. O. Box 66966
Phoenix, Arizona 85082

Gus - try to set up

June 15, 1994

Ms. Kristine Gebbie
National AIDS Policy Coordinator
750 17th Street NW, Suite 1060
Washington, DC 20503

Dear Ms. Gebbie:

During the last week of June, I and three other representatives of the National Parents' Council on AIDS (NPCA) will be meeting with members of the Administration and Congress to discuss the NPCA's recommendations for a national HIV policy. We would appreciate greatly the opportunity to present our recommendations to you, and to seek your advice about them and about ways in which the NPCA might most effectively support your efforts.

The NPCA is a 501(c)3 educational foundation emphasizing public education and, especially, public health policy issues. Our current recommendations address five issues in HIV policy: (1) the political struggle to control the AIDS case definition; (2) funding levels; (3) the special concerns of women, infants, children, and adolescents; (4) unrestricted public access to information about the epidemic; and (5) the urgent need for a national plan to cope with the epidemic.

For purposes of identification, I'll mention that I am also a professor of psychology at Arizona State University, where I co-chair the interdisciplinary HIV Studies Network. My son is Cleve Jones, founder of the AIDS Memorial Quilt and the NAMES Project Foundation, and a board member of NPCA.

We appreciate very much your efforts to help the Administration address the HIV pandemic more effectively--particularly your support of increased research efforts concerning the special needs of women and children--and hope we shall have the opportunity to meet with you. I can be reached at (602) 994-9028 or FAX (602) 945-5590.

Sincerely yours,

Austin E. Jones

Austin E. Jones, Ph.D.
President

AEJ:ee

Enclosures 2

Austin E. Jones, Ph.D.

Dr. Jones is Professor of Psychology and Co-Chair of the HIV Studies Network at Arizona State University, where he previously served as Director of the Clinical Psychology Training Program and Chair of the Department of Psychology. He received his Ph.D. from the University of Rochester and was a member of the faculty of the University of Pittsburgh prior to joining Arizona State University.

In 1988 Dr. Jones joined with others in establishing the National Parents' Council on AIDS (NPCA), which he serves as President. His son is Cleve Jones, founder of the AIDS Memorial Quilt and the Names Project Foundation, and a board member of NPCA.

Dr. Jones has been active in the Democratic Party for many years. He is presently a member of the Arizona State Democratic Committee.

National Parents' Council on AIDS

The National Parents' Council on AIDS (NPCA) was established in 1988 as a citizens' response to the HIV pandemic. The mission of the NPCA is to help the nation make a positive, united response to the pandemic through public education projects and through research and consultation concerning public health policy issues. The NPCA is a 501(c)3 nonprofit educational foundation incorporated in Arizona.

The NPCA develops syllabuses for small group educational experiences, publishes studies of public health policy issues, provides lecturers on HIV topics, sponsors conferences, and serves as a consultative resource to community and educational organizations and to government. In 1990, the NPCA sponsored the only national, public conference on AIDS policy ever held, with 46 panelists from medical, community, political activist, and governmental organizations; the keynote speaker was Dr. June Osborn, former chair of the National Commission on AIDS.

The *NPCA Quarterly Bulletin* attempts to fulfill a constructive role in providing analyses of the epidemiological, socio-political, and economic issues surrounding the HIV pandemic which will be useful to political leaders and public health professionals. In 1993, the NPCA published a research study evaluating the accuracy of information contained in the AIDS information brochures distributed by state departments of health throughout the country in 1992. An update of this research is currently in progress.

The NPCA is unique among AIDS organizations in being a citizens' initiative with a primary emphasis on public health policy. The organization is funded primarily by individual contributions and receives no funds from governmental agencies.

National Parents' Council on AIDS
P.O. Box 66966
Phoenix, Arizona 85082

June 23, 1994

Ms. Kristine Gebbie
National AIDS Policy Coordinator
750 17th Street NW, Suite 1060
Washington, DC 20503

Dear Ms. Gebbie:

We look forward to our meeting with you June 29 at 4:45 p.m. Enclosed is a copy of the recommendations of the National Parents' Council on AIDS which we would like to discuss with you.

Sincerely yours,

Austin E. Jones

Austin E. Jones, Ph.D.
President

AEJ:ee

Enclosure

Policy Recommendations for

Nat'l Council on HIV ~~+ AIDS~~

(1) Clarify to HIV
CDC to move into the
alignment of case definitions.

(2) Funding:

Ms. Jones Co-chair Univ. AIDS studies

Ruth - clinical / Social / Work
(Refugee Re-settlement)

Dwight - Engineer (Honeywell)
- Numbers / Parent

* * Parent / Counselor (HIV+ women)

1988 - founded → Phoenix

Contributors - National

* ADVOCACY for Research

→ what is the vision / Office?

* moving on prior guidance

→ Beaurocratic obstacles.

→ copy of AIDS events
- help publicize
- Television (frequently)

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NPCA Quarterly Bulletin

A Publication of the National Parents' Council on AIDS Fall 1993

Truth and Deception in AIDS Information Brochures

HIV disease and its terminal stage AIDS have been more extensively–and destructively–politicized in the United States than any other disease in the nation's history. This unfortunate phenomenon appears to have two principal sources. The first is the early and continuing stigmatization of AIDS as a disease of homosexual and bisexual men, although it was known by 1984 that AIDS in Africa and many other regions afffected mostly heterosexual men and women. Encouraged by–and sometimes encouraging–the antagonism felt by much of the public toward homosexuals, many conservative leaders found in the HIV epidemic both a basis for renewed attacks upon the gay community, and justification for opposing federal funding for AIDS programs.

The second source of the politicization of HIV disease arose more gradually, is ever increasing, and is at this moment enormously more potent than previously–the perception on the part of top political leaders that the HIV epidemic is a public health catastrophe of such gargantuan scale that no amount of federal money and political skill can fix it, at least not within the relatively short periods of time to which politicians feel they must limit their attention in order to survive. This perception may indeed be well-rooted in reality, in view of the estimated cumulative total of five million HIV disease cases in the U.S. by the end of the decade; thus it is understandable that most political leaders are immobilized by apprehension and a sense of futility. As the National Commission on AIDS observed in its 1991 report *America Living with AIDS*, "The lack of government leadership is everywhere evident."

While the annual rates of AIDS continue to rise, especially among heterosexual women and teenagers, in 1992 the overall federal funding for AIDS-related programs was virtually unchanged, in constant dollars, from the previous year. After more than a decade, there is still no national plan for responding to the epidemic. At the highest levels of government, the characteristic response to the HIV epidemic continues to be denial of its seriousness and avoidance of thinking about it.

When wars go badly–and this lop-sided war between humanity and HIV is going very badly indeed–governments have traditionally been loath to broadcast the bleak news to the citizens, lest confidence in the governments themselves falter. A skirmish won is portrayed as a turning point in the war, plans for action are reported as certain to be successful, and when all appears hopeless, the public may never be told, but left unprepared to experience the consequences of defeat first-hand.

While it is clear that governments frequently practice deception and secrecy with the justification that the public would become dangerously emotional and irrational if fully informed, there is no evidence that the public would in fact behave in that way. Rather, a fully-informed public, confident in the integrity of its government, will be more courageous and resourceful in coping with catastrophe than one from which its government keeps secrets.

AIDS information brochures distributed to the public serve, potentially, at least three critical functions in the war with HIV; these are the efforts to (1) prevent HIV infection, (2) control the public's emotional reaction to information about progress–or the lack of it–in the war with HIV, and (3) influence the public's cultural interpretation of the epidemic.

The first function is the publicly-stated or declaratory function of virtually all AIDS information brochures. The prevention of HIV infection is almost always approached from the standpoint of primary cause, principally sexual contact, shared needle usage, and the receipt of contaminated blood or blood products. (There are rare references to such indirect or secondary causal factors as poor nutrition and other factors which may weaken the immune system and increase the risk of infection.)

Functions (2) and (3) are never, it appears, declaratory, but even a quick reading of a small sample of AIDS information brochures suggests that they are important operational functions, though not explicitly identified. Regarding the second function, it is at least understandable–and perhaps rational in the short term–for governmental agencies to seek to control the level of fearful arousal elicited by public messages about the war with HIV, and to foster confidence in the agency issuing the information. Similarly, it should not be surprising that efforts to influence the cultural interpretation of the epidemic

CONTINUED

Recommendations for a National HIV Policy

National Parents' Council on AIDS

June 1994

Preface

In the following pages the National Parents' Council on AIDS discusses recommendations concerning five issues in HIV policy: (1) diagnostic terminology; (2) funding levels; (3) the special concerns of women, infants, children, and adolescents; (4) public access to information about the pandemic; and (5) the urgent need for a national plan to cope with the pandemic. These recommendations are to be presented to Congressional offices, members of the Administration, and officials of federal agencies in a trip to Washington in June 1994.

We understand these recommendations do not begin to exhaust the important topics for which policy recommendations are needed, but have selected these five issues because we believe they are particularly critical at this time. Many organizations have put forth comprehensive recommendations concerning the HIV pandemic which are of great value, and we are grateful for the extensive and thoughtful work they have accomplished. We endorse the recommendations of the 1988 report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic, the various reports of the National Commission on AIDS, the report of The Federal HIV/AIDS Agenda '93, and those of a number of other organizations to which we are indebted.

Recommendations for a National HIV Policy

National Parents' Council on AIDS

Issue 1--Diagnosis:

NPCA position. "AIDS" is an obsolete term, as it designates the terminal stage of HIV disease, which is always or almost always fatal. The practice on the part of federal agencies to count only "AIDS" rather than HIV disease fosters a serious misperception of the magnitude of the pandemic, and excludes an estimated more than one million Americans with HIV disease from federally-funded services that would extend their productive lives.

Discussion. In the early years of the HIV epidemic, it was thought that less than half of those infected with HIV would contract the illness called AIDS. With each successive year, however, estimates of the percent of those infected who would develop AIDS rose until, in July 1988, the Centers for Disease Control (CDC) estimated that more than 80% of HIV-infected persons would become clinically ill over an eight-year period. It is now widely believed that over a period of fifteen or more years, 99-100% of those infected with HIV will develop AIDS.

The evidence is very strong that infection with HIV initiates a continuous, slowly-developing disease with advanced stages characterized by what we now call AIDS. It has been clear for several years that there is no longer a rational basis for considering HIV infection and AIDS as separate categories. Therefore the National Parents' Council on AIDS again urges replacement of the diagnosis of AIDS with that of HIV disease. We believe it is imperative that this recommended change in nomenclature be adopted at once in order not to obscure further the magnitude of the pandemic. While we appreciate the efforts of the Centers for Disease Control, we believe the continued use of obsolete nomenclature is seriously misleading the public and policy-makers alike. Under the current nomenclature, there are now about 156,000 living persons for whom the AIDS diagnosis has been reported, but the reality is that there are an estimated one-to-two million people living with HIV disease, all or almost all of whom, it is believed, will eventually die should more effective treatments not be developed.

It is disturbing that this recommendation still needs to be made at this time. In the Executive Summary of the Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic (June 1988), the Presidential Commission listed its 20 most important recommendations. The first sentence of the first recommendation strikes directly at the heart of the issue: "*The term 'AIDS' is obsolete.*" The complete text of the first recommendation is as follows:

> *The term "AIDS" is obsolete. "HIV infection" more correctly defines the problem. The medical, political, and community leadership must focus on the full course of HIV infection rather than concentrating on later stages of the disease (ARC and AIDS). Continual focus on AIDS rather than the entire spectrum of HIV disease has left our nation unable to deal adequately with the epidemic. Federal and state data collection efforts must now focus on early HIV reports, while still collecting data on symptomatic disease.*

In 1988, the same year as that of the Presidential Commission's report, the Institute of Medicine of the National Academy of Sciences addressed the issue of diagnosis in its comprehensive report "Confronting AIDS: Update 1988." In the introduction of the Executive Summary, the Institute wrote:

> *It has long been apparent, however, that many HIV-infected persons suffer from clinical syndromes and laboratory test abnormalities that signal the presence of disease but do not meet the CDC criteria for AIDS.... By now, the committee believes that HIV infection itself should be considered a disease.*
>
> *Viewing HIV infection as a disease is important because it may eventually be amenable to treatment and patients will need to be diagnosed and treated as early as possible. Clinically, it is more accurate to describe HIV infection as a continuum of conditions associated with immune dysfunction. From a public health perspective the important event is infection rather than full-blown disease because even aymptomatic infected persons are capable of infecting others.*

Now, six years after the recommendations of both the Presidential Commission and the Institute of Medicine, the fundamental issue of the diagnosis remains unresolved. While the CDC's January 1, 1993 revision of the diagnosis to

include persons with T4 counts below 200–and to enlarge slightly the list of indicator diseases–moves minimally in the direction of acknowledging HIV infection as disease, it fails to clarify the fundamental reality that HIV disease is contracted with the initial HIV infection, and that HIV disease always or almost always leads to AIDS.

Nothing in the preceding discussion nor the recommendations which follow should be construed as arguments for linking the determination of disability to the diagnosis of HIV disease, for mandatory HIV testing, or for mandatory reporting of the names of those diagnosed with HIV disease.

Recommendations

A. (to federal health agencies--especially the Centers for Disease Control--and to the Council of State and Territorial Epidemiologists)

That infection with HIV be considered evidence of a single illness, called HIV disease, and the obsolete diagnoses of AIDS and ARC be immediately discontinued.

B. (to the Secretary of Health and Human Services)

That the Secretary of Health and Human Services direct the Centers for Disease Control to consider replacing the obsolete definition of AIDS with that of HIV disease for all who are infected with HIV, and to justify any decision to decline or to delay implementing such change in definition.

C. (to Congress for specific legislation)

That Congress direct that all persons with HIV disease, as evidenced by HIV infection, be accorded all the protections of civil rights, protection from discrimination, access to health and social services, and other benefits now accorded those persons diagnosed with AIDS.

D. (to Congress, as advice for future legislation)

That Congress, in all future legislation, discontinue use of the obsolete AIDS diagnosis as the means of identifying persons who are the subject of legislation, substituting in its place the diagnosis of HIV disease, which refers to all persons with HIV infection.

E. (to the President)

That the position of National AIDS Policy Coordinator be renamed "National Coordinator for HIV Disease Policy."

F. (to the National AIDS Policy Coordinator)

That the National AIDS Policy Coordinator,as a matter of the highest priority, take a leadership role in persuading the White House and federal health agencies to frame their thinking about the HIV pandemic in terms of HIV disease rather than of AIDS, and to discontinue use of the obsolete term AIDS.

G. (to the Surgeon General)

That the Surgeon General, as a matter of the highest priority, take a leadership role in persuading the White House, federal health agencies, and the public to frame their thinking about the HIV pandemic in terms of HIV disease rather than of AIDS, and to discontinue use of the obsolete term AIDS.

H. (to members of Congress)

That the General Accounting Office (GAO) be requested to (1) evaluate the CDC's estimate of one million in the U.S.infected with HIV as a basis for forecasting the pandemic in this country, (2) make recommendations of the most effective methodology for future studies concerning the prevalence and incidence of HIV infection, to be conducted in such a way as to fully protect the privacy of individuals participating in the studies.

Issue 2--Funding:

NPCA position. Relative to both the scale of human misery and the increasingly severe economic impact of the HIV pandemic, federal funding of HIV programs continues to be irrationally--and dangerously--low.

Discussion. In 1994, the total of US Public Health Service appropriations for research and development of vaccines and medical treatments for HIV disease was approximately $0.6 billion, and the appropriations for education and prevention programs were about $0.4 billion. The size of these investments in medical and educational efforts to cope with HIV infection or to prevent it has no logical relationship to the projected more than $100 billion in lifetime, direct medical

care costs for only the low-end estimate of one million Americans who now have HIV disease, or to the projected $600 billion in loss to the national economy because of their illnesses and premature deaths. If what many believe is a more realistic current estimate of 1.5 million cases of HIV disease in the U.S. is assumed, the total financial loss to the nation associated with only those now infected will exceed one trillion dollars--an amount roughly equivalent to one quarter of the national debt.

It is also instructive to compare HIV funding with that of other areas of national concern:

Appropriations for the Space Station in 1993	$ 2.2 billion
Total spent thus far on Star Wars	32.0 billion
Total spent thus far to rescue the Savings and Loan industry	150.0 billion
Additional appropriations to deal with the S & L crisis in 1994 alone	34.0 billion
Relief for victims of two major hurricanes in 1992	8.5 billion
Los Angeles area earthquake relief in 1994	9.5 billion
Research and development of HIV vaccines and medical treatment (1994 appropriations)	0.6 billion

We know of no one who would begrudge the assistance given the victims of hurricanes and earthquakes, but surely the lives of more than one million Americans should weigh at least as heavily on the national conscience.

Opponents of increased HIV funding continue to draw upon arguments which reflect ignorance of--or disregard for--critical features of HIV disease. It is often argued that cancer and heart disease kill more Americans than does HIV disease, but receive less funding; therefore there is no justification for increased appropriations for HIV disease. Such reasoning is faulty for several reasons:

(1) HIV disease is a commmunicable disease; cancer and heart disease are not.

(2) Cancer and heart disease affect older people principally, while HIV disease is a disease of the relatively young, with most of the deaths occurring to people between 20 and 50.

(3) Unlike cancer and heart disease, which have annual incidence rates that vary little from year to year, AIDS diagnoses continue to accelerate alarmingly; while reports of HIV disease cases are not uniformly collected by the CDC, there

is little reason to suppose that the underlying trend of HIV infections is not also accelerating.

(4) Because HIV disease kills mainly people in their reproductive years, it is expected that there will be tens of thousands of infants and young children whose mothers will have died of HIV disease--a phenomenon not occurring with cancer and heart disease.

(5) The vast majority of cancer and heart patients, being over 65, can get treatment through Medicare; by contrast, the majority of HIV patients are in the age range 20-50 and do not qualify for Medicare until two years after the AIDS diagnosis--at which time most are seriously ill or dead.

(6) Because most of the deaths due to HIV will occur among people in their most productive years of employment, the loss to the national economy because of their premature deaths will be many times greater than the loss due to deaths from cancer, heart disease, and other illnesses which strike principally older people who are no longer employed.

Comparisons of HIV expenditures with those for cancer and heart disease are especially problematic because figures cited for cancer and heart disease typically refer to research costs only, and treatment for those illnesses is mostly covered by Medicare, whereas the figures for HIV/AIDS also include the costs of prevention and treatment. It is important to note, further, that while there has been substantial medical progress in the treatment of cancer and heart disease, comparable progress in treating HIV disease has not yet occurred.

Perhaps the greatest irrationality in framing the funding debate as a competition between HIV disease and heart disease, cancer, and other illnesses lies in the failure to understand that increased funding of HIV research will almost certainly result in greater knowledge of immune system function generally--with benefits for patients across a broad spectrum of illnesses including cancer and heart disease.

We acknowledge that opposition to increased HIV funding is sometimes expressed by officials of the federal agencies responsible for HIV research and by members of Congressional committees dealing with budgetary matters. It is the public position of the NIH administration, and some members of Congress, that additional funding beyond the level currently proposed could not be absorbed by the present research system. We believe their conclusion is not correct, that it reflects intense pressures for political accomodation rather than an objective assessment of the capabilities of the nation's research resources. But if their conclusion

is held to be correct, then it is imperative that the present research system within NIH be quickly overhauled so that it can meaningfully absorb increased HIV funding. The limitations of existing NIH research structures cannot be accepted as an excuse for continued failure to fund HIV programs at a level proportional to the danger which HIV poses for the nation.

While detailed answers to the question of how increased HIV funding can best be deployed lie outside the intent of this paper, we offer the following suggestions as to how the questions should, in part, be approached.

The initial response from the health care community to the advanced stages of HIV disease, or AIDS, reflected the biomedical community's traditional approach to all disease--that diagnostic identification and ultimate control of symptoms, and cure (i.e., elimination) of disease, are the goals of all intervention strategies. Such an approach to any acute disease leads to heavy research emphasis on the biological causes of disease and focuses clinical interventions on the most symptomatic and ill individuals. While these research emphases should be continued, there is considerable evidence to support the development of an additional research emphasis which is directed to the earlier years of HIV disease and to the factors in long-term survivorship.

A small but growing number of individuals live for long periods of time (more than 10 years) following HIV infection without developing serious symptoms, and some individuals live long enough (more than three years) after the initial AIDS diagnosis to be considered long-term survivors of AIDS. The length and variability of these intervals has attracted the interest of researchers. Viral characteristics, response of immune system cells to infection, and the presence of co-factors, or those elements that make the infection worse in some patients, are under intense scrutiny. Additionally, a number of reports have addressed the apparent similarities of psychosocial characteristics among the long-term survivors and the role which these characteristics may play in the progression of HIV disease.

In addition to the traditional efforts to develop vaccines and to search for a cure, we believe there is substantial research evidence arguing for the development of a "third front" in HIV research–i.e., an emphasis on the interrelation of psychosocial and biomedical factors in determining the course of HIV disease–in other words, the application of the interdisciplinary field often referred to as psychoneuroimmunology. The field of psychoneuroimmunology investigates the relationships between the emotional state, nervous and endocrine systems, and the immune system's ability to resist disease. The principles of psychoneuroimmunology suggest that psychosocial factors can significantly influence the course of

illness in an immune-compromised individual. While we believe that psychoneneuroimmunological research should be rapidly expanded, it is also essential, we believe, that the traditional biomedical approaches to vaccines and the search for a cure not only be continued, but also substantially expanded; the failure thus far of those efforts does not, of course, mean that success will never come.

Recommendations.

A. (as advice to the President and the Congress in their consideration of the budgets for 1995 and succeeding years)

1. That it be acknowledged now that the vast scale of the HIV pandemic in the United States is such that expenditures in the tens of billions of dollars for HIV-related programs (exclusive of current entitlement programs) must be anticipated within the next few years.

2. That the total USPHS budget for HIV-related programs be increased to $4.5 billion in FY95, and increased further to $7.5 billion in FY96. If this is not accomplished in the normal budget process of the Congress, the President should request the additional funding as an emergency measure.

3. That within the total USPHS budget, the allocations for research and clinical trials of vaccines and medical treatments be increased to at least $1.2 billion in FY95, the allocations for research on educational prevention programs be increased to $1.2 billion in FY95, and each of these categories be increased further to at least $2.8 billion in FY96.

B. (to the National AIDS Policy Coordinator)

That the National AIDS Policy Coordinator take a leadership role in advocating increased HIV funding within the White House and federal agencies, and with Congress.

Issue 3--The special concerns of women, infants, children and adolescents.

NPCA position. Despite the fact that the incidence of AIDS diagnoses has been rising more rapidly in women than in men for the past several years, women continue to be discriminated against in the diagnosis of AIDS, inclusion in clinical trials, and access to both experimental and fully-approved treatments. Infants, children, and adolescents usually experience the same forms of discrimination, in

addition to the devastating emotional consequences of their mothers' illnesses and premature deaths.

Discussion.

Shifting trends in HIV infection. It is well known that HIV disease in the early years of the U.S. epidemic was centered in the gay male population of San Francisco and other large cities. Both the Reagan and Bush administrations fostered the stigmatization of HIV disease as a concern principally of gay men, although it was known by 1984 that HIV disease in Africa and many other regions affected mostly heterosexual men and women. In the U.S., after the initial concentration of HIV disease in the gay community, the epidemic grew rapidly among injection drug users and, from them, was introduced into the heterosexual population, particularly women.

Over the past several years, HIV transmission rates for gay and bisexual men have been declining, while the rates for women and teenagers have been accelerating alarmingly. In 1992, the percentage increase among women (9%) was 3.6 times greater than the increase among men (2.5%). According to projections by Dr.David Michaels, an epidemiologist at the New York Medical School, the HIV pandemic will leave between 72,000 and 125,000 American children and adolescents motherless by the end of the decade.

While women presently constitute only about 10% of the diagnosed AIDS cases, it appears likely that the majority of new HIV disease cases will be women by the end of this decade. There is now strong research evidence that women are more than 14 times more likely to become infected in heterosexual relationships than are men. Thus, although women presently represent only about 10% of AIDS diagnoses, it appears virtually certain that the incidence of HIV disease in women will continue to rise more rapidly than in men.

Exclusion of women in HIV research and treatment. It is a matter of great concern to the National Parents' Council on AIDS that the expression of HIV disease in women has generally been ignored as a topic of research study. The unwarranted assumption has been that HIV disease in men and women is essentially the same, and that there is no need to evaluate possible differences in the way in which HIV disease affects men and women. As a consequence, women have been systematically excluded from clinical trials, and even from receiving the AIDS diagnosis as they were dying of HIV disease.

There is considerable evidence that HIV disease in women is often expressed in a pattern of infectious diseases and cancers which differs significantly

from that of men. The new case definition of AIDS makes it somewhat more likely than before that women with HIV disease will qualify for the AIDS diagnosis, but falls far short of assuring women equal access to clinical trials and other medical and social services. Not only are women discriminated against on the basis of their gender, but also because they are women with HIV disease. As Mary Beth Caschetta has written in a recent SIECUS report, "...women with HIV disease, a life-threatening illness, continue to be excluded from clinical trials of experimental HIV treatment, unlike, for instance, women with cancer, who are routinely granted the use of experimental cancer treatments, even those thought to be harmful to a fetus. The discrimination against women with HIV disease in this particular situation is undeniable."

Eliminating discrimination against HIV-infected women. The first remedy is to eliminate immediately the term "AIDS" from official use as a diagnostic category, as we previously recommended. Treatment and prevention programs should be designed specifically to meet the unique socioeconomic, cultural, educational, and medical needs of HIV-infected female populations. Clinical trials should be designed to attract the largest number of female participants possible, from diverse ethnic backgrounds, with the ultimate goal of separate and numerically equal clinical trials for men and women.

Ensuring that women have equal access to other health services is more complex. Not only women but also infants, children and adolescents all experience various forms of discrimination. In 1991, the NPCA recommended that all federally funded programs for HIV disease be evaluated to determine the adequacy of their support for the welfare of women, infants, children, and adolescents. Government should exercise leadership in establishing national program standards and guidelines responsive to the special needs of women, infants, children, and adolescents who have HIV disease or who are at increased risk. In particular, the USPHS should:

a. establish standards and requirements for respite care and family support services for individuals and families affected by HIV disease, especially HIV-infected mothers of young children;

b. develop guidelines and monitor program performance for ensuring that HIV-infected infants, children, and adolescents who are wards of the state receive prompt, appropriate, and adequate attention to their medical needs, and that wards of the state not known to be infected have ready access to HIV testing;

c. establish standards for comprehensive parent/family education on the specialized health, nutritional, medical and personal hygiene needs of HIV-

infected women, infants, children, and adolescents;

d. develop guidelines and monitor program performance to ensure sufficient child care, transportation, community linkages, and educational and family support resources for HIV-infected mothers and their children so that they can fully participate in treatment in the least restrictive environment; in addition, ensure that programs are designed to attract and fulfill the special needs of women without stigmatizing them;

e. develop guidelines and monitor program performance to ensure that all HIV-related educational, diagnostic, and treatment services are fully and readily available to women, infants, children, and adolescents of color; in addition, ensure that programs are designed to attract and fulfill the special needs of people of color without stigmatizing them;

f. develop guidelines and monitor program performance to ensure that educational, diagnostic, and treatment services are fully and readily accessible to heterosexual, homosexual, and bisexual adolescents, both male and female; in addition, ensure that programs are designed to attract and fulfill their special needs without stigmatizing them;

g. establish research and treatment facilities more widely throughout the United States to better serve HIV-infected women, infants, children, and adolescents with less need for lengthy travel or extended absences from home and family.

Recommendations.

A. (to the Secretary of Health and Human Services)

1. That the Secretary of Health and Human Services direct that all federal agencies conducting programs concerning HIV disease provide for the nondiscriminatory representation of women, infants, children, and adolescents in all aspects of basic research, clinical trials, and access to both experimental and fully-approved treatments.

2. That the Secretary of Health and Human Services direct the establishment of national program standards and guidelines responsive to the special needs of women, infants, children, and adolescents who have HIV disease or who are at increased risk of infection; such standards and guidelines should be developed for all federally funded programs which provide HIV-related services.

3. That the Secretary of Health and Human Services direct annual evaluations of the programs of the National Institutes of Health with respect to the adequacy of their funding, staffing, and programs for HIV disease in women, infants, children, and adolescents.

B. (to the Secretary of Education)

That the Secretary of Education (1) direct the establishment of national standards and guidelines for HIV education in public schools, K-12, to ensure that all students receive full information concerning the transmission of HIV and the means of preventing HIV infection; and (2) foster HIV educational programs which include the presentation of factual information concerning all risk behaviors, whether heterosexual or homosexual in nature.

C. (to the USPHS and the President)

Where additional funding and staffing are required for HIV programs for women, infants, children, and adolescents, such support should not be provided at the expense of other HIV-related programs.

D. (to the Surgeon General)

That the Surgeon General take a leadership role in public education programs concerning the special concerns of women, infants, children, and adolescents, especially through regular appearances on network television.

E. (to the National AIDS Policy Coordinator)

That the National AIDS Policy Coordinator take a leadership role in fostering effective cooperation among the federal health and education agencies with respect to programs which address the special needs of women, infants, children, and adolescents.

Issue 4--Free and unrestricted public access to information about the HIV pandemic:

NPCA position. The citizens of the United States have a right to accurate and complete information about all aspects of the HIV pandemic; neither the federal nor any other level of government should withhold, censor, or delay the release of information related to HIV disease--except to protect the privacy of individuals--or engage in deception about any aspect of the pandemic.

Discussion. There is some basis for concern that both deception and secrecy have been practiced by federal agencies over a prolonged period. In a review of the HIV/AIDS information brochures distributed to the public by state departments of health (many of which were published by federal agencies), the NPCA found that more than two-thirds of the brochures included statements judged seriously misleading--and in every instance, the effect of the misleading statement was to portray HIV infection and AIDS as less dangerous than almost universally believed by medical researchers. This evidence suggests, but does not prove, that the widespread inclusion of misleading statements in AIDS information brochures represents the systematic practice of deception in order to minimize the public's emotional reaction to the epidemic.

Motivation to restrict the public's knowledge of the epidemic is evident also in governmental habits of secrecy. Former Surgeon General Koop states in his memoirs that throughout the first Reagan administration, he was forbidden by the White House even to mention the word AIDS in a public meeting. Although it would be difficult to estimate the number, we believe it probable that many lives were lost as a consequence of the censorship of Dr. Koop's speech. In the second Reagan administration, that ban was lifted but other efforts to control information about the pandemic continued. At least through 1988, important scientific reports on HIV and AIDS were submitted by the CDC to the Domestic Policy Council for review and editing before being released to the public.

Sissela Bok, in her highly-regarded book *Lying: Moral Choice in Public and Private Life*, notes that the most prominent excuses for lying invoke a moral principle. First among them are the principles of avoiding harm and producing benefit, and both appear to underlie the deceptions and secrecy of the government regarding the HIV pandemic. Especially compelling as a justification for lying, in the view of governments and individuals alike, is the conviction that a crisis exists where only deception can prevent overwhelming harm. Bok develops this point in the following passage:

> *At times, those who govern also regard particular circumstances as too uncomfortable, too painful, for most people to be able to cope with rationally. They may believe, for instance, that their country must prepare for long-term challenges of great importance, such as a war, an epidemic, or a belt-tightening in the face of future shortages. Yet they may fear that citizens will be able to respond only to short-range dangers. Deception at such times may seem to the government leaders as the only means of attaining the necessary results.*

While it is clear that political leaders frequently practice deception and secrecy with the justification that the public would become dangerously emotional and irrational if fully informed, there is no evidence that the public would in fact behave in that way. Rather, a fully-informed public, confident in the integrity of its government, will be more courageous and resourceful in coping with catastrophe than one from which its government keeps secrets. Indeed, habits of secrecy and lying on the part of government may make it very difficult for the public to respond constructively when a catastrophe can no longer be concealed.

Recommendations. (to the President and the Secretary of Health and Human Services)

A. (to the President and the Secretary of Health and Human Services)

1. That the President and the Secretary of Health and Human Services publicly declare, and then carry out, a policy of free and full disclosure of information concerning all aspects of the HIV pandemic, except for information which would violate the confidentiality of individuals.

2. That the President and the Secretary of Health and Human Services declare that classification of HIV information as secret will not be permitted. If classification of such documents has occurred, that fact should be acknowledged and the affected documents made public.

3. That the President and the Secretary of Health and Human Services publicly declare, and then act accordingly, that no policy of prior review, editing (except that which is needed for clarity), censorship, or delay in reporting of scientific or other information about the HIV pandemic or any other public health concern will be imposed upon, or permitted within, any federal or other governmental organization, nor imposed upon any non-governmental agency or individual.

B. (to the National AIDS Policy Coordinator)

That the National AIDS Policy Coordinator advocate a policy of free and full disclosure of information concerning all aspects of the HIV pandemic (except for information which would violate the confidentiality of individuals) to the President, Domestic Policy Council, and all federal health and education agencies.

C. (to the Surgeon General)

That the Surgeon General (1) advocate a policy of free and full disclosure of information concerning all aspects of the HIV pandemic (except for information which would violate the confidentiality of individuals) to the President, Domestic Policy Council, and all federal health and education agencies; and (2) implement that policy in regular appearances on network television.

Issue 5--The absence of a national plan for the HIV pandemic:

NPCA position. Now, after more than a decade of the HIV pandemic, it is unacceptable that the federal government has not yet formulated a plan for responding effectively to the pandemic, despite the fact that an estimated one-to-two million persons in the United States are now infected with HIV, and the rate of AIDS diagnoses in the U.S. is accelerating. Continued failure on the part of the President, the federal agencies, and the Congress to respond decisively to the HIV pandemic can only result in inexpressible misery for millions of Americans, and extreme economic stress for the nation as a whole, including the collapse of the health care system as we know it.

Discussion. The federal government appears to be immobilized by anxiety over its premonition that vast sums of money will be required to cope with the pandemic and that success is by no means assured. The characteristic response of the government to the pandemic continues to be denial of its seriousness and avoidance of thinking about it. What political leaders appear to fear even more than the catastrophe of the pandemic itself is the anticipated reaction of the public when it realizes that the pandemic is not under control, and that no national plan exists for helping the health care system deal with its impact.

That there is indeed no national plan for dealing with the HIV pandemic has been pointed out forcefully by both the Presidential Commission and the later National Commission on AIDS. We have already cited the conclusion of the Presidential Commission (1988) concerning the obsolete nature of the term "AIDS," but a portion of that statement belongs here as well:

> *Continual focus on AIDS rather than the entire spectrum of HIV disease has left our nation unable to deal adequately with the epidemic.* (underlining added)

In December 1989, the National Commission on AIDS, having been officially chartered by the Congress only four months before, expressed its concern in

the following statement:

> *There is no national plan for helping an already faltering health care system deal with the impact of the HIV epidemic....To date, there is no national policy or plan, and no national voice.*

And again in September 1991, the National Commission on AIDS repeated its warning:

> *The lack of government leadership is everywhere evident.*

One of our colleagues recently expressed the issue to us in these plain words: "We are now at a stage of despair. We need hope--and it can only come from strong political leadership."

Recommendations.

A. (to the President)

That the President (1) publicly identify the HIV pandemic in the U.S. as an urgent matter of national concern and accept personal responsibility for guiding the nation's response to the pandemic in a televised address to the Congress; (2) state that he, the Secretary of Health and Human Services, and the National AIDS Policy Coordinator will work intensively and closely together to oversee the development of a national plan for responding effectively to the pandemic, (3) pledge that he and the Administration will work in cooperative partnership with the Congress in the development of such a plan, and (4) address the nation on network television at least once each quarter for the purpose of reporting on the current status of the pandemic and the plans and actions of the federal government for dealing with it.

B. (to the Congress)

That the Congress pass a resolution (1) identifying the HIV pandemic in the U.S. as an urgent matter of national concern, and acknowledging its responsibility for guiding the nation's response to the pandemic in a televised session with the President, (2) pledging that the Congress will work in cooperative partnership with the President and the Administration in the development of such a plan.