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Subseries:

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National Aids Policy
Kristine Gebbie

2 of 9

SEPTEMBER, OCTOBER & NOVEMBER 1993 CHRON FILES

SEPTEMBER CHRON FILES

1993

7299

THE WHITE HOUSE

WASHINGTON

September 1, 1993

Ms. Marylouise Welch
Chairperson of the Fund raiser Dinner
Connecticut Nurses' Foundation, Inc.
377 Research Parkway, Suite 2D
Meriden, Connecticut 06450

Dear Ms. Welch:

Thank you for your kind letter of congratulations. I would be honored to speak at your fund raiser dinner this winter. Please call Ms. Retina Holmes at (202) 690-5471 to make the necessary arrangements.

I look forward to seeing you.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

THE WHITE HOUSE

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National AIDS Policy Coordinator

Prepared by: APO: TFox: gw: 9/2/93: 690-5471: b:\foxltrs.gbe/welch.gbe

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

Reply —
Thanks —
Yes —
work with
Peter Holmes
to schedule

CNF

July 5, 1993

Dear Ms. Gebbie,

I met you several years ago at a NANDA Publicity Committee meeting with Derry Moritz. I am writing you today on behalf of the Connecticut Nurses' Foundation. On the heels of the ANF very successful dinner and fund raiser with Marion Wright Edelman, the CNF is interested in sponsoring a fund raiser dinner in the winter and we are asking if you would have the time to be our speaker.

The goal and format would be similar to ANF. The foundation would share some of the profits with one of the AIDS projects in Connecticut. We would be happy to work with you about which group. We would also need to discuss this with the Connecticut Nurses' Association Board of Directors.

We were considering one of the winter months and either New haven or Hartford for location. We would be very flexible about both of these and would like to accommodate the speaker. We would be happy to provide a modest honorarium and your expenses.

I hope you will consider this as an opportunity to help nursing scholarship as well as service for AIDS patients and to continue to help connect nursing with other groups working on behalf of the public health.

Congratulations on your appointment and I hope you will seriously consider this invitation.

Thank you.

Sincerely,

Marylouise Welch

Marylouise Welch,
Chairperson of the Fund raiser Dinner

CONNECTICUT NURSES' FOUNDATION, INC.

377 Research Parkway • Suite 2D • Meriden, Connecticut 06450 • 203-238-1207

7303

THE WHITE HOUSE

WASHINGTON

September 1, 1993

Ms. Bonnie R. Henriquez
4611 Allendale Avenue
Oakland, California 94619

Dear Ms. Henriquez:

Thank you for taking the time to write and voice your concerns about the AIDS epidemic. I agree that research is needed to support and expand both service and prevention efforts.

As the National AIDS Policy Coordinator, I will strongly support a response to the epidemic that demonstrates a commitment to HIV research and caring for those who are infected.

I appreciate hearing from you.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

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Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Prepared by: APO: TFox: 8/31/93: 690-5560: b:\foxltrs.gbe\henriquez.gbe

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

We same reply as
Similar letter in the
batch

—

HENRIQUEZ
4611 ALLENDALE AVE
OAKLAND, CA 94619

OAKLAND CA
4PM
21 AUG
1993

Kristine Gebbie
AIDS Coordinator
White House
Washington, D.C. 20500

August 21, 1993

Kristine Gebbie, A.I.D.S. Coordinator.

I agree with you that in order to get a handle on the AIDS epedemic, we must educate everyone, adults and children alike.

My question to you is why you emphasized education and did not mention accelerating research monies so that we can find a cure for this illness.

There are approximately 1.5 million people that are HIV positive. Have you just forgotten about these lives?

Yes, we must educate. We must also increase research.

Please don't forget the already infected.

Sincerely

Bonnie L. Henriquez
4611 Allendale Ave
Oakland, CA 94619

THE WHITE HOUSE

WASHINGTON

September 1, 1993

Ms. Shirley A. Coleman
1833 Parker Street
Berkeley, California 94703

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National AIDS Policy Coordinator

Prepared by: APO: TFox: 8/31/93: 690-5560: b:\foxltrs.gbe\coleman.gbe

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

Thanks
agree research needed
to support & expand both
Service & prevention efforts

—

Shirley A. Coleman
1833 Parker St.
Berkeley, CA 94703

OAKLAND CA
SEP
21 AUG
1987

29 Hyacinth
USA

Kristine Gebbie
AIDS Coordinator
White House
Wash D.C. 20500

1833 Parker St.
Berkeley Ca 94703
8-20-93

Dear Ms. Gebbie

I am pleased with your efforts in support of AIDS education. However with at least 2 million Americans identified as HIV positive there is an urgent need to identify all promising cures / treatments and obtain their timely and adequate testing outside of the realm of the NIH and pharmaceutical companies. Independent innovative research is needed now.

Yours truly
Shirley A. Coleman

THE WHITE HOUSE

WASHINGTON

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Oakland, California 94619

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National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

September 2, 1993

Ms. Pamela Haughton-Denniston
Director of Public Affairs
The Center for Population Options
1025 Vermont Avenue, N.W.
Suite 210
Washington, D.C. 20005

Dear Ms. Haughton-Denniston:

Thank you for writing, and sharing information regarding adolescent health. Our young are indeed an important, vulnerable population.

I agree that prevention programs are key to mounting an effective response to the HIV epidemic. Prevention will be a major part of my agenda as the National AIDS Policy Coordinator. Accomplishing prevention will take many activities to both educate individuals and support them in a lifetime of wise behavior choices.

I appreciate your offer of assistance and that of Dr. Clarke.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

September 2, 1993

Ms. Patricia C. Gorton
3853 Ingraham C-316
San Diego, California 92109

Dear Ms. Gorton:

Thank you for writing and sharing your concerns about the transmission of the human immunodeficiency virus (HIV).

Although I am not aware of research involving the transmission of HIV via saliva in swimming pools, overwhelming evidence indicates that this would be a highly unlikely mode of transmission. Studies designed to test transmission of HIV through saliva have demonstrated that it does not occur.

If you would like information on HIV research, please write to the:

Office of AIDS Research
National Institutes of Health
NIH Building 1, Room 201
9000 Rockville Pike
Bethesda, Maryland 20892

Office for HIV/AIDS
Centers for Disease Control and Prevention
Executive Park Building
1600 Clifton Road, N.E.
Mail Stop - D21
Atlanta, Georgia 30333

While I support widespread HIV antibody testing as a part of our national effort to limit the spread of HIV, I do not think mandatory testing is appropriate. We must, however, continue consideration of any appropriate actions.

Again, thank you for sharing your thoughts with me.

Sincerely,

Kristine M. Gebbie, RN, MN

THE WHITE HOUSE

WASHINGTON

September 2, 1993

Mr. David A. Bolender
800 Pacific Avenue, #408
Long Beach, California 90813-4247

Dear Mr. Bolender:

Thank you for taking the time to write and share your views on HIV-related issues.

I believe it is possible to craft a scientifically sound and responsible program of public health efforts, medical care and education which can limit the further spread of HIV. As I begin my responsibilities, I will be looking for ways to include all perspectives on this epidemic in our policy deliberations.

Again, thank you for sharing your thoughts with me. It will take the efforts of all Americans to stem this epidemic.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

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National AIDS Policy Coordinator

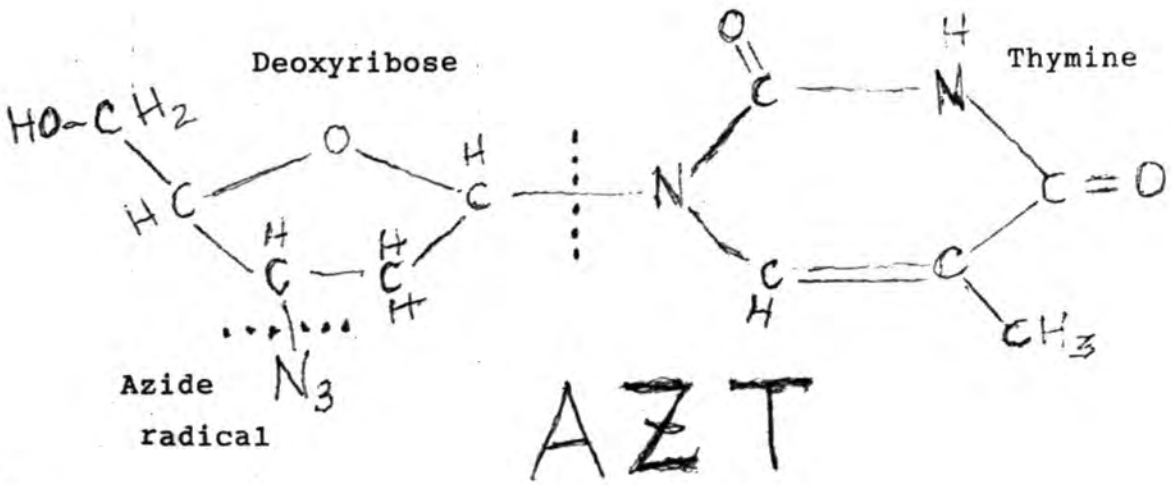
Prepared by: APO: TFox: 9/9/93:202-690-5560:b:\foxlts.gbe\bolender.gbe

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

Draft reply

AZT ANALOGS



Deoxyribose---Thymine
|
N_3

Three other versions of AZT are possible using the DNA bases: adenine, guanine or cytosine in place of thymine. And many killer radicals are possible instead of the azide radical.

Chloride, bromide, Iodide, fluoride and their derivatives like chloromethyl, difluoro-ethyl or tribromopropyl; arsenic derivatives like dimethyl arsine, arsenate, arsenite, and similar phosphorous and antimonyderivatives, hydrazine and other nitrogen compounds.

To the DNA bases or uracil or deoxyribose or ribose or combinations of these DNA and RNA components can be attached whole compounds like atoxyl, neosalvarsan, aspirochyl, amino phenol, organic mercury and sulphur compounds or anti-biotics like terramycin.

Two part molecules composed of virus bait and a virus killer or immobilizer may be the answer for an AIDS cure.

-Cl -$CHCl_2$ -F -CH_2CF_3 -Br
-$CHBr-CH_2Br$ -I -$CHOH-CI_3$

-$NH-NH_2$

-Terramycin

-$O-Hg-O-\overset{O}{\overset{\|}{C}}-CH_2-CH_2OH$

-CH_2-CH_2SH

General formula= DNA virus bait plus killer radical

-$As(CH_2CH_2OH)_2$

-$O-\overset{O}{\overset{\|}{As}}-O-Na$

-$P(CH_2CH_2NH_2)_2$

-$C_6H_4NH_2$

-$C_6H_3(OH)NH_2$

-$O-\overset{O}{\overset{\|}{Sb}}-O-Na$

-$C_6H_3(OH)Cl$

-$CHOH-CH_2NH_2$

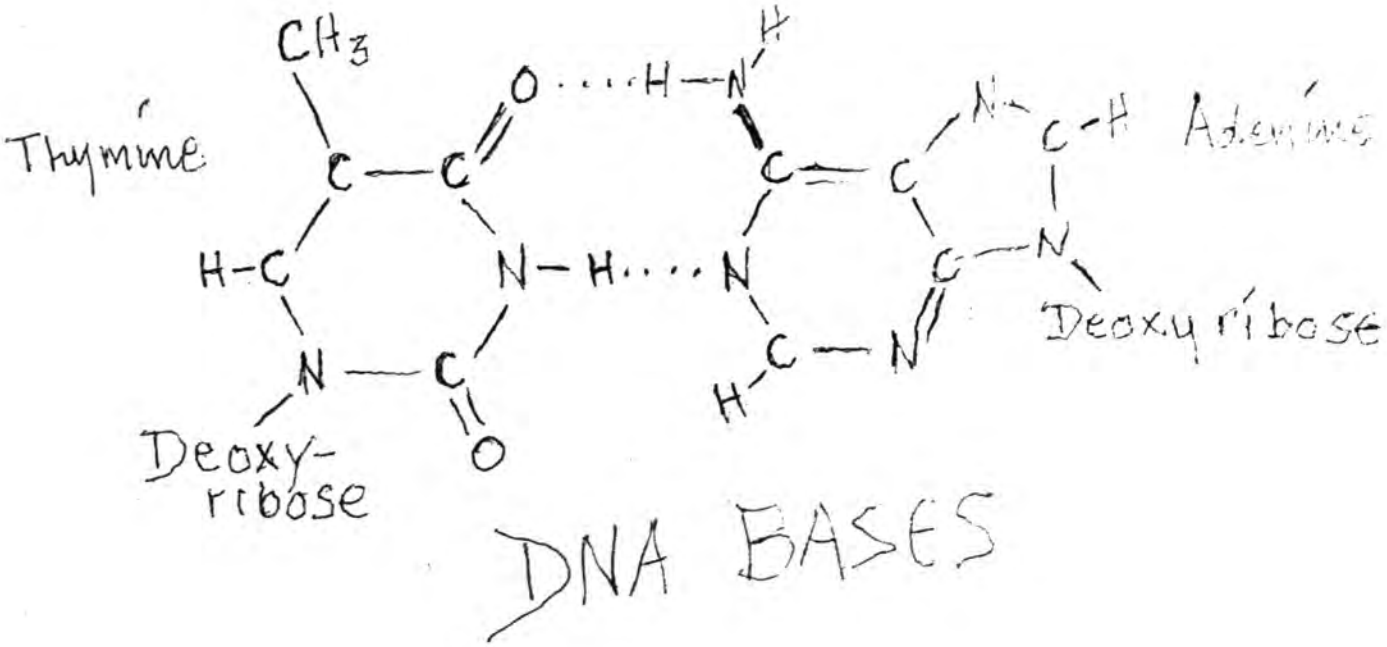
-$CH(NH_2)-CH_2SH$

-$As-C_6H_3(NH_2)(OH)$

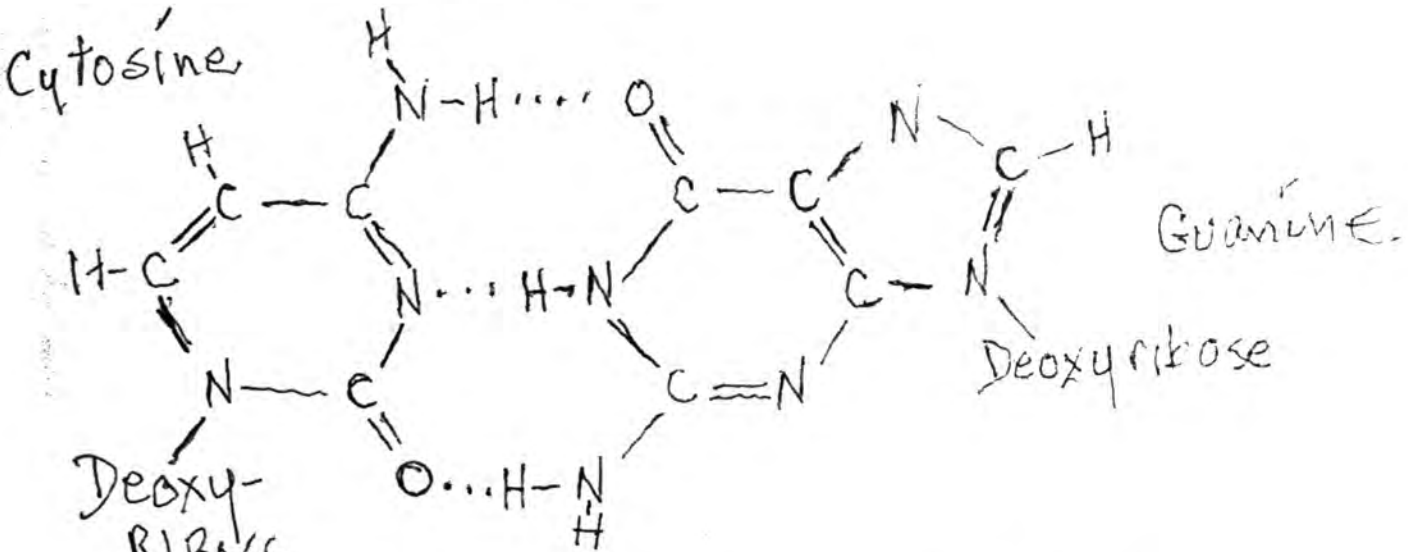
-$S-(CH_2CH-CH_2NH_2)$

Anything not patented before Nov 1993 belongs to the U.S. government - Valid A-ISO vendor

DNA BASES ATTACHMENT POINTS



DNA BASES



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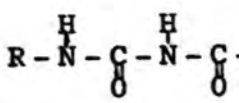

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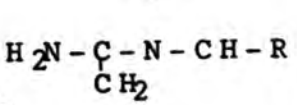

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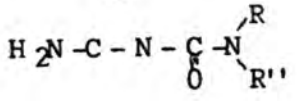
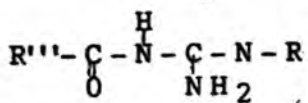


G



R is a killer radical. See A Z T page. R' is a methyl or CH_2OH, etc. R'' Is an H or alcohol or sugar. Any unfilled valence are filled with H.

24 August 1993

Dear AIDS CZAR:

a cure is needed for AIDS. Not more AZTs which are effective on some people for some of the time; or AL 721 which has to be taken every day. A cure you take once or a few times and the disease is gone for good. Thousands have died and millions are at risk. A cure is needed now.

There are two kinds of AIDS medicines: those like AZT that are based on DNA, and those like AL 721 that attack the virus membrane. AL 721 is made from eggs which should make it cheaper and more readily available than AZT etc. which are made from fish sperm if the quality control problem can be solved. However neither of these drugs is a permanent cure.

You say you don't want a Manhattan type project but you are wrong. During World War II a number of projects were done successfully including a program to produce sythetic rubber. Something like that is needed now. A lot of time has been wasted. You should stmcture your office to produce results. Otherwise government burocrats and your subordinates will be running things. One of your subordinates should be a chemist.

You may need Congressional legislation to override patent claims and to stop exorbitant drug pricing as well as getting exact cost figures from drug companies. The government could maunfacture AL 721 or a later version and guarantee quality.

Since placebo tests have killed dozens of AIDS victims before their time, placebo tests should be banned. When a likely cure is found, it should be tested first on Rhesus monkeys for safety and if it is safe, then given to AIDS sufferers.

A prevention program should emphasize three things: 1) Abstinence, 2) Hygiene and 3) Condoms in that order. An individual does not need sex to live a long happy life. Happiness comes from work, religion or philosophy and relationships with people and sexual acts are not necessary.

Being squeaky clean before and after sex reduces the chance of catching AIDS or any other venereal disease. Of course, any program will illustrate the consequences of V.D.; sterility, paralysis, etc. up to and including death.

Condoms should be freely available. After World War II U.S. occupation forces followed different programs to eliminate V.D. The Far East Command emphasized condoms and pro-kits; the European theatre tried more moral coercion. The European theatre had a higher V.D. rate.

Candidate Clinton proclaimed two goals: a cure for AIDS and the restoration of the AIDS victim's immune system. Talking to people may not acheive this though you should talk to the leaders and experts of ACT UP. Best wishes.

sincerely yours,

David A. Bolender

David A. Bolender
800 Pacific Ave, #408
Long Beach, CA 90813-4247

29 Sep 1993

Try feeding myelin orally(the nerve sheath protein) to AIDS victims where the disease is attacking the central nervous system. The PBS program SECRET OF LIFE(10 pm, 28 Sep 93) reported that myelin was taken orally to stop the process of MS. This may work against AIDS in the central nervous system.

Best to you and your cause,

David A. Bolender

David A. Bolender
800 Pacific Ave, #408
Long Beach, CA 90813-4247

LONG BEACH CA 908 42
PM
29 SEP
1993

USA 19

AIDS Czar Kristine Gebbie

THE WHITE HOUSE

Washington, DC 20500

THE WHITE HOUSE

WASHINGTON

September 2, 1993

Women of Color Leadership Forum
C/O National Minority AIDS Council
300 Eye Street, N.E., Suite 400
Washington, D.C. 20002-4389

Dear Friends:

I would be delighted to meet with your group to discuss the concerns women of color have about HIV infection, and ways we can work together to bring you into the policy and planning process.

You mention two meetings of concern to your members. The first is a scheduled review of all Healthy People 2000 Objectives related to HIV; this is part of a series routinely scheduled with the Assistant Secretary for Health. I am participating actively, and plan to use the meeting to promote the effective community partnerships we need if we are to achieve our goals.

The second date is I think in error. You may be referring to a meeting scheduled by the Latino AIDS Education Leadership, which has invited me to speak about my new role, and about the epidemic. You may wish to speak directly to Irma Maldonado who is the organizer of this meeting. She can be reached at (202) 452-0092.

I am looking forward to the results of your forum in Miami, and to working together. Please have someone call Retina Holmes at (202) 632-1090 to schedule a meeting.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

CC:

Dr. Donna Shalala
Dr. Philip Lee
Dr. Jocelyn Elders
Dr. Jo Ivey Bufford
Dr. Audrey Manley
Ms. Patsy Fleming
Ms. Sarah Kovner
Ms. Michelle Wilson
Dr. Vicki Mays
Ms. Nancy Heinrich
Ms. Leslie Wolfe
Mr. Steve Morin
Ms. Cindy Hall
Ms. Kelly O'Brien
Ms. Constance Miller
Ms. Elena Alvarado
Ms. Jennifer Chambers
Ms. Toni Young
Mr. Warren Buckingham

WOMEN OF COLOR LEADERSHIP FORUM

TO : **SANDY BART**

FROM : **GAYLE TERRY**

DATE : **SEPTEMBER 3, 1993**

RE : **REQUESTED ADDRESSES**

MEMORANDUM

Pursuant to your telephone conversation with Cheryl McClellan, please find below the requested addresses. Should you need any further assistance, feel free to call Cheryl or me at (202) 544-1076.

Ms. Michelle Wilson, Executive Director
The Positive Woman
1959 4th Street, N.E.
Washington, D.C. 20002-1211

Dr. Vicki Mays
Black Care Project
1823 Franz Hall
Los Angeles, California 90024-1563

33/25.

Ms. Nancy Heinrich
Human Services Program Manager
Florida Department of Health and Rehabilitative Services
1390 N.W. 14th Avenue
Miami, Florida

Ms. Leslie Wolfe
Center For Women's Policy Studies
2000 P Street, N.W., Suite 508
Washington, D.C. 20036

Mr. Steve Morin
Appropriations Associate
Representative Nancy Pelosi
240 Cannon House Office Building
Washington, D.C. 20515-0508

Ms. Kelly O'Brien
Legislative Assistant
Senator Paul Simon
SD 462 Dirksen
Senate Office Building
Washington, D.C. 20510-1302

Ms. Cindy Hall
Legislative Director
Representative Constance Morella
233 Cannon House Office Building
Washington, D.C. 20515-2008

Ms. Constance Miller
Legislative Assistant
Representative Maxine Waters
1207 Longworth Office Building
Washington, D.C. 20515-0535

Ms. Elena Alvarado
Hispanic Designers Incorporated
1000 16th Street, N.W., Room 401
Washington, D.C. 20036

Ms. Jennifer Chambers
105 9th Street, S.E., #201
Washington, D.C. 20003

Ms. Toni Young
9007 Eton Road
Silver Spring, Maryland 20901

THE WHITE HOUSE

WASHINGTON

September 2, 1993

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300 Eye Street, N.E., Suite 400
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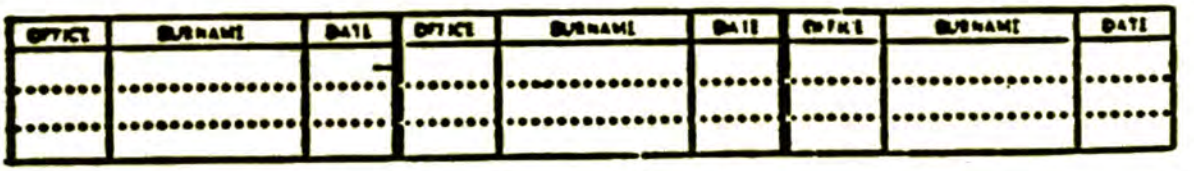

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Dr. Audrey Manley
Ms. Patsy Fleming
Ms. Sarah Kovner
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Mr. Steve Morin
Ms. Cindy Hall
Ms. Kelly O'Brien
Ms. Constance Miller
Ms. Elena Alvarado
Ms. Jennifer Chambers
Ms. Toni Young
Mr. Warren Buckingham

Prepared by: APO: KMGebbie: gw: 9/9/93: 632-1090: b:\women.asc

9/3/93

Sandy B:

File w/ltr.

Retira

WOMEN OF COLOR LEADERSHIP FORUM

September 1, 1993

Ms. Kristine M. Gebbie
Special Assistant to the President
National AIDS Program Office
Hubert H. Humphrey Building
200 Independence Avenue
Room 73-8G
Washington, D.C. 20203

Dear Ms. Gebbie:

It has come to the attention of the Women of Color Leadership Forum that a meeting has been scheduled for September 7, 1993 to brief you, and on September 13, 1993, a congressional delegation, concerning the issue of HIV/AIDS as it infects and affects women in this pandemic.

We understand that, as of July 1, 1993, the CDC HIV/AIDS Surveillance Report shows a cumulative total of 36,690 women with AIDS. Of this number, Black, Hispanic, Asian/Pacific Islander, American Indian/Alaska Native total 27,289 with White women totaling 9,330. Additionally, 2,401 of the 4,462 cases of children with AIDS, come from the cities of New York, the greater Miami, Florida area (Miami, West Palm Beach, Fort Lauderdale), Newark, New Jersey, Chicago, Illinois, Los Angeles, California, Baltimore, Maryland, Washington, D.C. and Boston, Massachusets. 243 children in Puerto Rico have AIDS.

To our knowledge, the planning process for these meetings has excluded adequate diverse representation of women of color. In particular, women of color, self-identified as living with HIV have not been invited to actively participate in the entire process. This is unacceptable.

We, the Women of Color Leadership Forum, perceive this exclusion to be disempowering; the implication is that we are unable to speak for ourselves about a matter that is crucial to our very existence. We, therefore, propose the following:

- That the scheduled meeting as currently constituted be cancelled.
- That a new meeting date be scheduled to enable our group to develop a diverse representation of women of color to meet with you.

Any other meeting that purports to develop and design an agenda to address the complex issues of women and AIDS without our leadership would be insensitive, inadvisable and inappropriate. The issues of women and HIV/AIDS where over 74% of the women living with AIDS are women of color, can be neglected no longer. We look forward to working with you and we will call your office to set up a meeting.

Sincerely,

Charon Asetoyer
Charon Asetoyer, Executive Director
Native. Am. Women's Hlth. Ed. Resource Center

Luz Martinez
Luz Martinez, Director
National Latina Health Organization

Dazon Dixon
Dazon Dixon, Executive Director
Sister Love, Incorporated.

Pandora Singleton
Pandora Singleton, Coordinator
Azuka

Norma Baker
Norma Baker, Executive Director
Northern Educational Service, Inc.

J C Wilkerson
Jacquelyn Wilkerson, Director
AIDS Advocacy/African Am. Churches

B.G. Beach
Barbara Gomes-Beach, Executive Director
Multicultural AIDS Coalition, Inc.

Teresa Chief Eagle
Teresa Chief Eagle, Native American
Women's Health Ed. Res. Center

Miguelina Maldonado
Miguelina Maldonado, Executive Director
Hispanic AIDS Forum

Mary Chung
Mary Chung, Executive Director
API For Reproductive Health

Zaida Castillo
Zaida Castillo

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Charlene Doria-Ortiz, Interim Dir.
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Suki Terada Ports, Director
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Ashanti Project

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Gayle L. Terry
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Vivian Torres
Vivian Torres, Coordinator
Vivian's Place

Yvette C. Burton
Yvette C. Burton

Marie St. Cyr-Delpe
Marie St. Cyr-Delpe, Director
Iris House, Incorporated.

cc: Donna Shalala, PhD., Secretary for Health and Human Services;
Phillip Lee, M.D., Assistant Secretary for Health;
Jocelyn Elders, M.D.;
Jo Ivey Bufford, M.D., Office of the Assistant Secretary for Health;
Audrey Manley, M.D., Office of the Assistant Secretary for Health;
Patsy Fleming, Special Assistant to the Secretary for Health and Human Services;
Sarah Kovner, Special Assistant to the Secretary for Health and Human Services;
Michelle Wilson, Director of the Positive Woman;
Vicki Mays, PhD. U.C.L.A.;
Nancy Heinrich;
Leslie Wolfe;
Steve Morin;
Cindy Hall;
Kelly O'Brien;
Constance Miller;
Elena Alvarado;
Buck Buckingham;
Jennifer Chambers;
Toni Young.

NATIONAL MINORITY AIDS COUNCIL

A QUESTION OF PARITY

WOMEN OF COLOR LEADERSHIP FORUM

AUGUST 26-28, 1993
MARCO POLO HOTEL
MIAMI BEACH, FL

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NATIONAL MINORITY AIDS COUNCIL

NMAC Update

July 1993

Report on the IX International Conference on AIDS

...This conference was one of the most critical for the future of AIDS research worldwide.

On June 7,1993, approximately 14,000 delegates representing 166 nations participated in the IX International Conference on AIDS in Berlin, Germany. It was clear that this conference was one of the most critical for the future of AIDS research worldwide. The conference served as a catalyst that has forced the AIDS community to reevaluate AIDS research strategies and to take a closer look at the drug development process. The new scientific data presented in Berlin not only dampered, but crumbled the previous knowledge that had been attained through years of research. More questions than answers came out of the conference, and the treatment options for those living with HIV/AIDS seem to be limited.

Although our frustrations were intensified by the news from the conference presenters, it provided those of us on the frontline with a reality check. We now have no doubt that there is a need for new approaches to finding a cure. In this issue we take a look at Pathogenesis and early treatment, the Concorde study, antiretroviral therapy and the guidelines developed by an independent panel of experts at the National Institutes of Health as a result of the conference.

Pathogenesis and early treatment

Pathogenesis is the term used to describe disease progression. Dr. Anthony Fauci of the National Institute of Allergy and Infectious Diseases (NIAID) gave a presentation on the pathogenesis of HIV infection at the first plenary session in Berlin. Dr. Fauci described HIV replication as a constant disease process. HIV actively replicates throughout the course of infection, even in the early stages when little viral activity can be detected in the blood. Researchers had believed that lack of viral activity in the blood of HIV infected, but asymptomatic individuals meant the virus was latent during this period. Due to sophisticated investigation techniques, we know that following primary infection, HIV is widely disseminated during the acute

Continued on next page

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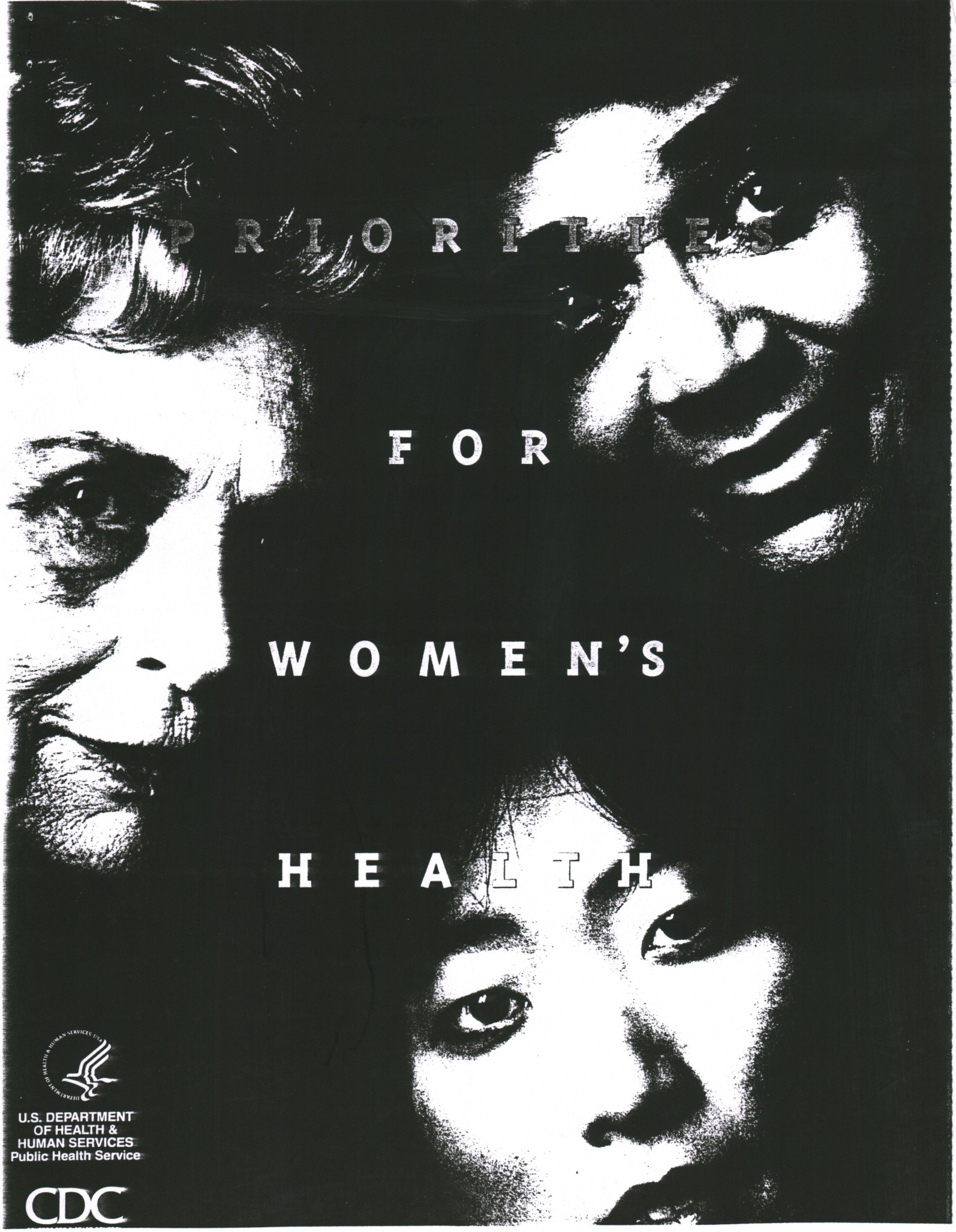


U.S. DEPARTMENT
OF HEALTH &
HUMAN SERVICES
Public Health Service

CDC

Preventing HIV/AIDS

During the past 10 years, the AIDS epidemic has been a major focus of public health attention. AIDS, or the acquired immunodeficiency syndrome, is caused by the human immunodeficiency virus (HIV). HIV/AIDS is now the sixth leading cause of death among American women ages 25 to 44. By October 1992, nearly 26,000 AIDS cases among adult and adolescent women had been reported, representing nearly 11% of all cases.

About half of the women with AIDS acquired HIV infection through intravenous drug use, and about one-third through heterosexual contact.

The number of reported AIDS cases among women increased 17% between 1990 and 1991, with only a 4% increase in cases among men. About 75% of women with AIDS are African American or Hispanic.

National Effort Launched

CDC is the nation's lead agency for HIV education, prevention, surveillance, and population-based research. Specifically, it:

- Monitors the extent of the HIV/AIDS epidemic,
- Conducts studies on the natural history of HIV infection in men, women, and children,
- Identifies risk factors for transmission and develops recommendations to prevent or reduce behaviors or practices which transmit HIV, and
- Supports HIV testing services to help individuals learn if they are infected with HIV and to improve referral to appropriate prevention and treatment services.

Surveillance. CDC has conducted national surveillance of AIDS cases since 1981 and supports nationwide, anonymous HIV infection surveys of selected populations of women, including patients attending women's health clinics and women being treated at sexually transmitted disease (STD) clinics. Surveillance of health care workers exposed to HIV-infected blood is also under way in approximately 300 health care institutions nationwide. A prospective study is being initiated to examine needlestick injuries and other exposures among nurses in 23 hospitals.

Public Information. CDC provides prevention messages to women through its *America Responds to AIDS* campaign, National AIDS Hotline, and National AIDS Clearinghouse. In 1990 alone, 43% of the nearly one million calls to the hotline were from women.

Training. CDC has a partnership with the American Red Cross to reach women at increased risk of HIV infection. The collaborative effort includes outreach, training of more than 1,000 female instructors nationwide to provide HIV and AIDS education at the community level, and development of educational materials.

In conjunction with the Public Health Service's Office of Population Affairs, CDC is supporting the training of family planning professionals in HIV prevention. In one such project, the Family Planning Council of Southeastern Pennsylvania is training family planning and substance abuse staff in the prevention of HIV infection in women.

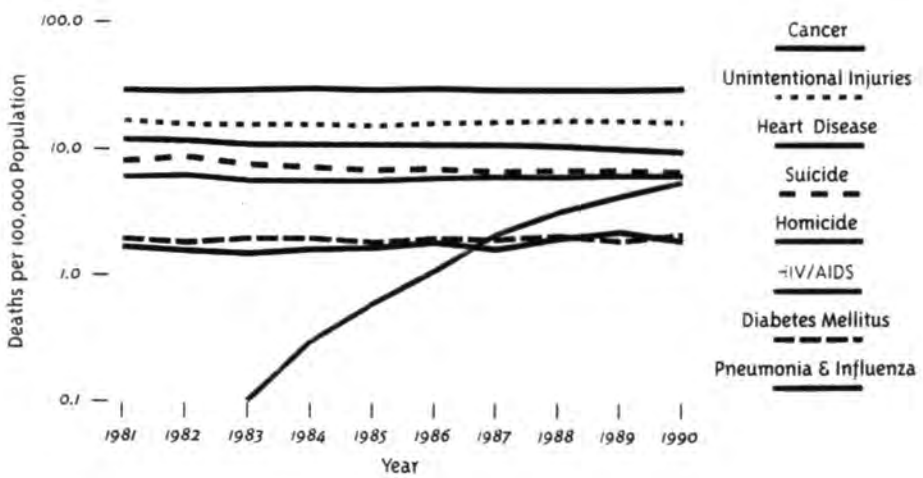
Local Programs Supported

Community-Based Education/Risk Reduction. CDC funds national, regional, state, and local community-based organizations that provide health education/risk reduction and public information activities. In 1993, women will be a priority for about half of the 32 national and regional organizations and 16 of the 42 newly funded local organizations.

In addition, the U.S. Conference of Mayors (USCM) has received CDC support since 1984 for HIV prevention, service, and needs assessment activities in local organizations serving women. Five of these organizations were highlighted in a 1991 USCM report entitled, *Women and AIDS/HIV.*

Expanded Counseling and Testing. Many women seek HIV/AIDS counseling and testing in nontraditional sites, such as STD clinics, tuberculosis clinics, women's health clinics, prenatal clinics, and drug treatment centers. CDC is supporting these sites and assessing the unique counseling needs of women in each setting.

Services for Injecting Drug Users. CDC supports state and local health department services for injecting drug users who are infected with HIV. Counseling and intervention for this population ideally should include the client's sex partners and other drug users with whom they share needles. Critically important are intervention services targeting adolescents and youths who are just initiating drug use by injection.



Death Rates for HIV/AIDS and Other Leading Causes
Women 25-44 Years of Age, 1981 - 1990

Prevention Clues Sought

Prevention Research. Several ongoing HIV studies are designed specifically to improve prevention efforts for women. In collaboration with the National Institutes of Health, CDC initiated the HIV Epidemiology Research Study to investigate the natural history of HIV disease in women and to characterize risk factors for conditions indicative of AIDS in women. CDC has also awarded funds to eight sites for a demonstration project to prevent HIV infection among women and infants.

During 1991, in collaboration with the Office of Population Affairs, CDC conducted a study in three cities (Seattle, New York, and San Francisco) to evaluate HIV prevention services in clinics serving primarily African American, Hispanic, and Native American women. Findings will be used to establish guidelines and training for clinic managers and other staff. Other projects are evaluating:

- The relationship between various behaviors, including cocaine and other drug use, and STDs in adolescent females.
- The effectiveness of a variety of strategies for increasing contraceptive use among women at high risk of HIV and women with HIV infection who do not wish to become pregnant.
- Programs in seven communities to prevent further transmission of HIV. Five have women's issues as a focus.
- Community-level behavioral interventions, including the creation of volunteer and peer networks for women to promote and reinforce risk reduction.
- New approaches to service delivery, including the provision of enhanced family planning services in nontraditional settings where women with, or at high risk for, HIV infection may be reached.
- AIDS related knowledge and behavior among women 15-44 years of age.
- Gynecologic disorders in HIV-infected women.
- Causes and clinical course of pelvic inflammatory disease in women with and without HIV.
- Risk of cervical cancer in HIV-infected women.

Case Study

Project CARES

Comprehensive AIDS and Reproductive Health Education Study (Project CARES) is a five-year study with sites in Baltimore, Philadelphia, and San Francisco. The study aims to develop and evaluate clinic-based activities to prevent HIV infection and unintended pregnancy among women who are at risk for HIV infection or already infected. Each site will use different strategies to reach women who need family planning services and to make those services readily available (e.g., provision of services in drug treatment centers, homeless shelters, and adult and pediatric HIV clinics). Women receiving services at all sites will receive similar counseling to help them overcome barriers to contraceptive and condom use.

Promoting Reproductive Health

Some illnesses and health conditions are unique to women. Among these are conditions related to reproduction: menstruation, pregnancy, childbirth, and menopause. In addition, access to safe and effective contraception is a critical health care need of women.

Women's reproductive health issues are as diverse as they are complex, and in many cases can be addressed through educated lifestyle and behavioral choices. The goals of CDC's reproductive health program are to prevent illness and death associated with reproductive occurrences, practices, and choices, and to promote adoption of healthy reproductive behaviors and environments, including work settings.

Contraception. In 1988, contraception was used by about 60% of American women of reproductive age. Birth control pills were the choice for more than 10.7 million women, and sterilization was the leading birth control method among currently married couples and formerly married women.

Pregnancy and Delivery. American women have more than six million pregnancies every year. For every 100 hospital births in 1986 and 1987, about 22 women were hospitalized for pregnancy-related complications not associated with delivery.

Pregnant women who receive no prenatal care or care starting in the final trimester are nearly three times more likely to die of pregnancy-related complications such as hemorrhage, embolism, pregnancy-induced hypertension, and infection. While maternal deaths have steadily decreased for all races over the past decade, the risk of death has been consistently higher for African American and other minority women — regardless of age — than for white women.

Women with *established* (diagnosed before conception) or *gestational* (with onset or first recognition during pregnancy) *diabetes* are also at particular risk of pregnancy-related complications. Women with established diabetes comprise about 1% of all pregnant women and are at greatly increased risk for ketoacidosis, urinary tract infections, preeclampsia, and eye, kidney, and nerve complications. Gestational diabetes occurs in up to 3% of pregnancies and is a major risk factor for the mother's subsequent development of diabetes.

Other serious complications of pregnancy and delivery include: *preeclampsia* (toxic condition including elevated blood pressure, kidney damage, and edema); *abruptio placentae* (premature separation of the placenta from the uterus); and *placenta previa* (blood clotting disorder from a low-lying placenta).

From 1983 to 1988, 35% of births were unintended; of these, 10% were unwanted. Of the approximately 1.1 million women ages 15-19 who become pregnant each year, 84% do not intend to do so.

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Reproductive Tract Disorders. More than 10% of all hospitalizations among women of reproductive age are due to reproductive tract disorders. One-third of all American women have a hysterectomy by age 60, translating into 570,000 hospitalizations each year.

A rare but devastating disorder, toxic shock syndrome, occurs in two of every 100,000 women ages 15-44 each year. The condition occurs most often in young women who use tampons or barrier contraceptives, during or shortly after their menstrual periods.

Contraceptive Practices Evaluated

Oral Contraceptives and Cancer. CDC's Cancer and Steroid Hormone (CASH) Study examined the relationship between the use of oral contraceptives and breast, ovarian, and endometrial cancer. Analyses showed that women who use oral contraceptives reduce their risk for both endometrial and ovarian cancer by 40%.

As a follow-up to CASH, CDC will be the data coordinating center for a seven-year, population-based, case-control study initiated by the National Institute on Child Health and Human Development in 1992 to assess the relationship between the risk of breast cancer and the use of oral contraceptives among women ages 40-64 years. This new study will examine breast cancer among women who were among the first to use 'the pill' when it was introduced, and who now are entering the ages that are at highest risk for breast cancer.

Characteristics of Women Who Choose Norplant. Women who choose Norplant, contraceptive hormonal implants effective for five years, and women who choose other methods of contraception are being interviewed at Johns Hopkins University School of Hygiene and Public Health to determine demographic and behavioral characteristics. The data from this CDC-supported study will also be used to examine the characteristics of women who have unintended pregnancies.

Complications of Sterilization. CDC's Collaborative Review of Sterilization (CREST) was initiated in 1978 as the largest prospective study of the complications of tubal sterilization in the U.S. CREST has enrolled and followed more than 12,000 sterilized women, along with a comparison group of more than 500 women whose husbands have had vasectomies. Selected health consequences being examined include surgical complications, subsequent hysterectomy rates, changes in menstrual function, sterilization failures, regret after sterilization, and rates of sterilization reversal.

Program Consultation. CDC consults with interested national, state, and local health departments in the use of management tools to improve clinical communication systems, layout, and design; patient flow analysis to document patient movement and staff use; surveillance of family planning services; state and local level reproductive health surveys; and evaluation.

The agency is currently collaborating with the Arizona State Health Department in a statewide telephone survey of the reproductive health practices of 3,000 women ages 18-44, with a particular focus on minority populations. The Hawaii School of Public Health Prevention Center is also receiving assistance with a similar survey of women 15-44, of whom more than 60% are Asian Americans or Pacific Islanders.

Services to Developing Countries. CDC assists countries interested in improving their management and operation of reproductive health and family planning services. From 1989 to 1993, 13 countries will have received assistance with reproductive health surveys. These countries include Belize, Brazil, China, Costa Rica, Czechoslovakia, Dominican Republic, Ecuador, El Salvador, Haiti, Jamaica, Mauritius, Nicaragua, and Romania.

Pregnancy Outcomes Improved

CDC serves as one of the primary federal resources for technical assistance in the epidemiology and surveillance of pregnancy and its outcomes. Working collaboratively with agencies and organizations at all levels, the agency evaluates the nation's pregnancy-related health problems, programs, and policies in an effort to improve the health of pregnant women and their infants.

Surveillance of Pregnancy-Related Conditions. CDC has monitored pregnancy-related mortality since the 1970s and has recently developed a new National Pregnancy Mortality Surveillance System to better identify maternal deaths, classify the causes of death into meaningful clinical categories, and identify risk factors for maternal death. CDC also supports surveillance of diabetes during pregnancy in 15 states and American Samoa.

Maternal Studies. Specific investigations over the years have focused on deaths related to abortions, ectopic pregnancies, and AIDS, among others. During the past three years, CDC has been analyzing data on maternal morbidity from the National Hospital Discharge Survey and conducting facility-based studies of pregnancy complications. These include a study of ectopic pregnancy at Grady Memorial Hospital in Atlanta, Georgia; studies of pregnancy-induced hypertension at the Marshfield (Wisconsin) Clinic and at the facilities of the Indian Health Service's Navajo Area Office; and a study of complications of induced abortion at Reproductive Health Services in St. Louis, Missouri.

Unintended Pregnancies. With CDC support, Emory University is identifying determinants of unintended pregnancy among teens and adult women. Focus groups will examine the cognitive processes associated with answering survey questions about the timing and prevention of unplanned pregnancy and contraceptive decision-making.

Gynecologic Disorders Monitored

Surveillance. CDC maintains a passive national surveillance system for case reports of menstrual and non-menstrual toxic shock syndrome to assess the magnitude of illness and follow trends in disease occurrence. Consultation is provided to the Food and Drug Administration on toxic shock syndrome and tampons.

CDC also periodically examines the number and characteristics of women who undergo hysterectomies.

Occupational Research. CDC studies closely the reproductive health effects on women of various occupations and work place exposures. Current projects are examining:

- Chemicals with potential reproductive toxicity to both males and females.
- Effects of physical and mental job stress, and stress-related behaviors like caffeine consumption, on menstrual function and ovarian hormone patterns.
- Feasibility of conducting reproductive studies of female flight attendants (in collaboration with the Federal Aviation Administration) and dental assistants exposed to mercury.
- Effects of farm worker activities and exposures on the reproductive health of women living in California farming communities.

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1993 National Skills Building Conference

OCTOBER 31 – NOVEMBER 3

HYATT REGENCY

NEW ORLEANS

PLEASE JOIN US
FOR THE LARGEST GATHERING
OF FRONT LINE AIDS WORKERS
IN THE COUNTRY.

AIDS NATIONAL INTERFAITH NETWORK • NATIONAL ASSOCIATION OF PEOPLE WITH AIDS • NATIONAL MINORITY AIDS COUNCIL

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An Invitation to Exhibit

1993 National Skills Building Conference

OCTOBER 31 – NOVEMBER 3

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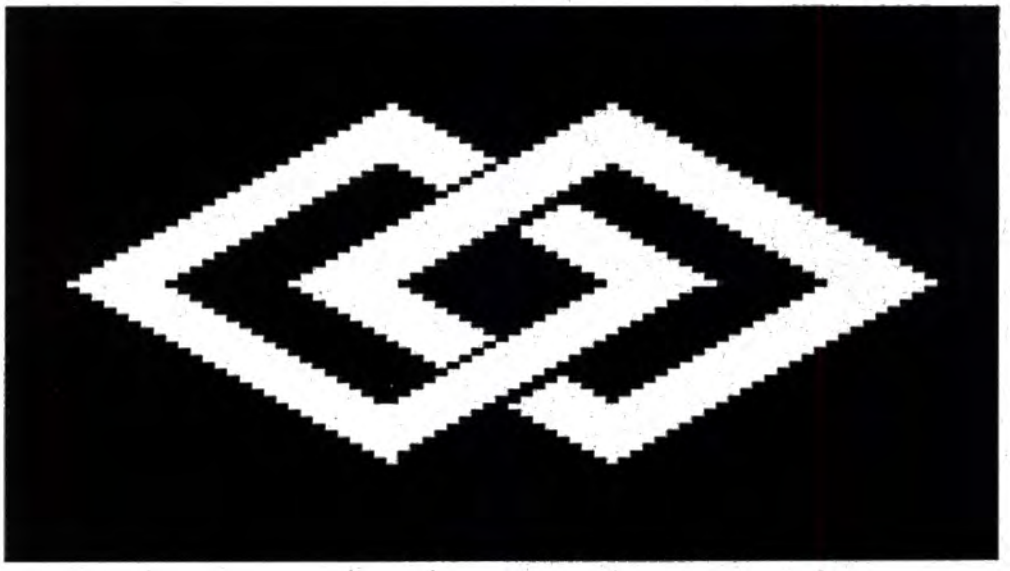
NEW ORLEANS

WOMEN OF COLOR LEADERSHIP FORUM



OUR HEALTH AND HIV :
A QUESTION OF PARITY
A MANDATE FOR INCLUSION

FRIDAY, AUGUST 27, 1993
AND
SATURDAY, AUGUST 28, 1993

THE MARCO POLO HOTEL
MIAMI BEACH, FLORIDA

WOMEN OF COLOR LEADERSHIP FORUM
"HIV AND OUR HEALTH:
A QUESTION OF PARITY...
...A MANDATE FOR INCLUSION"

August 26th -29th, 1993
Marco Polo Hotel, Miami Beach, Florida

Thursday, August 26, 1993

6:00 - 7:30 p.m. Registration

7:30 p.m. Informal Reception

Friday, August 27, 1993 ***Compass Room***

8:00 a.m. Continental Breakfast

8:30 a.m. Opening Remarks and Welcome
Marie St.Cyr-Delpe
N.Y. Foundation for Women

9:00 - 10:45 a.m. Section I
Women and HIV: Symptoms and Symptomatic Situations

A discussion of Women's health issues as they relate to and are intertwined with HIV concerns, i.e., reproductive health and issues of choice.

Mary Chung
Asian Pacific Islanders for Reproductive Health
Luz Martinez
National Latina Health Organization

Friday, August 27, 1993 (continued)

11:00 a.m. - 12:30 p.m. Section II

Women of Color and HIV Education: What Works for "Them" May Not Work For "Us"

A frank discussion on the need to develop or, at a minimum, determine the standards and guidelines necessary for effective outreach and education concerning women's health and effective access to comprehensive health care.

Dazon Dixon
Sister Love, Inc.
Tonia Schaffer
AIDS Education and Prevention
Chicago Department of Health

12:30 - 2:00 p.m. Luncheon -- ***Penthouse Room***

2:15 - 3:45 p.m. Session III

A Matter of Governance: Who Speaks For Women of Color, If Anyone?

Questions to be raised and discussed in this session include: Do women in positions of power advocate women's issues generally? Do they address issues of women's health? Do the women or other individuals who promote women's health with regard to HIV adequately address the needs of women of color? Can those needs be better articulated by women of color? Should we develop and promote leadership on these issues within our own communities?

Marie St. Cyr-Delpe
N.Y. Foundation for Women
Suki Terada Ports
N.Y. Family Health Project

4:15 - 5:30 p.m. Session IV

Our Health in Mind, Body and Spirit

The importance of spirituality to women of color and the role spirituality plays in health promotion to women living with or at risk for transmission of HIV.

Jacquelyn Wilkerson
AIDS National Interfaith Network.
Charon Asetoyer
Native American Women's Health Education Resource Center
Vivian Torres, Executive Director
Vivian's Place

Saturday, August 28, 1993 ***Compass Room***

8:00 a.m. Continental Breakfast

9:00 - 10:45 a.m. Session V
Current Trends in Health: A Question of Parity

A discussion on access, or the lack thereof, to clinical trials and health information to women of color.

S. Denise Rouse
Office of the Assistant Secretary for Health

11:00 a.m. - 12:45 p.m. Session VI
How We Communicate: "Can We Talk?"... Do We?

A dialogue about how we communicate our needs to our partners, to our physicians, to our communities and to each other. An additional discussion about the invisible women in communities of color-Lesbians.

Vivian Torres
Vivian's Place
Yvette Burton
N.Y. City Dept. of Health

12:45 - 2:00 p.m. Lunch *(on your own)*

2:00 - 3:45 p.m. Session VII
So, Who's Getting All The Attention And Where Are Those Dollars Going?-A Mandate for Inclusion

Where are the research concentrations and dollars? A discussion surrounding the need for adequate and accurate information/reporting regarding women of color and incidents of HIV infection. Moreover, the obligation to properly incorporate and effectively disseminate the reported information within communities of color.

Marie St. Cyr-Delpe
N.Y. Foundation for Women
Suki Terada Ports
N.Y. Family Health Project

3:45 - 5:00 p.m. Closing Session
Prioritizing our Needs.....Literally

An opportunity for forum participants to articulate and outline our concerns and needs. Discussion regarding a report on this forum and whether we should concentrate efforts on a National Conference.

5:00 p.m. Adjourn

WOMEN OF COLOR LEADERSHIP FORUM

A Question of Parity
A Mandate for Inclusion

Issues of Women's Health are not high priority concerns in Communities of Color. Getting children to school, feeding them, keeping them away from drugs and out of jail are, for example, very real concerns and are often viewed as more urgent and of greater priority in our communities than our own health. It comes as no surprise then that, well over a decade after beginning the battle against HIV infection, women's health concerns in this regard have been, and continue to be, woefully neglected. Yet, by the year 2000, we will comprise the majority of AIDS cases in the United States (*National Commission on AIDS, Final Report, p. 6*). In one year alone, between 1991 and 1992, the cases of AIDS among women increased by 9 percent, while during that same time period, the cases among men increased by 2.5 percent.

To date, neither HIV surveillance nor research initiatives have been established which adequately target women living with or at risk of HIV transmission. (*NMAC, The Impact of HIV on Communities of Color. 1992 p. 11*). Sadly, the gross lack of attention given to women's issues concerning HIV infection is merely reflective of the inept discussion, initiatives, and genuine leadership surrounding women's health issues in general. The lack of focus on women's health issues, particularly AIDS-related issues, however, has resulted in an even greater disparity between the health needs of women in communities of color and the resources available to fight

the HIV/AIDS epidemic. Compounding this problem is the fact that women's health issues concerning HIV are too often defined by those who have little or no knowledge about the *women most affected by HIV disease: women of color.* While African American and Hispanic women represent only 21 percent of all U.S. women, they account for over 77 percent of the women with AIDS. (*National Commission on AIDS, Final Report, p. 6*). Despite the very devastating effect HIV has had within communities of color, no comprehensive resources of AIDS information are currently available to, or about, women of color.

This national forum, therefore, is a call to action for women of color to define our own issues, develop our own leadership and to demand sufficient resources with which we can then effectively address this epidemic. Women of color and our issues concerning HIV have, for too long, been the afterthought. It is now time the "afterthought" come to the "forefront" in the battle against AIDS. The Women of Color Leadership Forum will mark the first time during the history of the HIV/AIDS epidemic that concerned, committed, and experienced women of color will come together to address the very urgent issues of women's health particularly as it relates to HIV disease. The forum will witness a wonderful collective of women sharing ideas, providing input and insight into the development of an educational report and a national advocacy platform.

- As of December, 1992, 253,448 cases of AIDS were reported to the Centers for Disease Control and Prevention. Of these, 27,485 were women;

- According to CDC estimates, women are the fastest growing group of people with HIV/AIDS;

- HIV seropositivity is now nearly equal among men and women in several tested populations in the U.S., including groups of armed services recruits, certain urban populations, and Job Corps candidates;

- Women with HIV are often the primary caregivers in families in which the partner and children are also HIV-positive;

- The risk of male to female transmission of HIV during heterosexual sex is higher than that of female to male HIV transmission;

- **Women of Color are disproportionately infected with HIV. While American African and Latina/Hispanic women represent only 21% of the U.S. female population, we account for over 77% of all women living with HIV.**

OUR HEALTH AND HIV
A QUESTION OF PARITY
A MANDATE FOR INCLUSION

The National Minority AIDS Council (NMAC) would like to thank each of you for your participation and the following folks for their patience and efforts in creating this Women of Color Leadership Forum:

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Executive Director

Weather

Today: Partly sunny, windy, thunderstorms. High 96. Low 70. Wind west 10-20 mph.
Friday: Partly sunny. High 86. Wind northwest 10-20 mph.
Yesterday: Temp. range: 75-100.
AQI: 105. Details on Page B2.

The Washingtn

116TH YEAR .... No. 236

THURSDAY, JULY 29, 1993

AIDS Spreads Fastest Among Young Women

U.N. Study Finds Adolescents On Epidemic's Leading Edge

By Boyce Rensberger
Washington Post Staff Writer

Among sexually active people, those being infected with the AIDS virus at the fastest rate are women in their teens and early twenties, including many who have had relatively few sex partners.

As women grow older, they become less likely to contract the virus even though, on average, their number of sex partners increases. Men, by contrast, do not encounter their peak risk for AIDS infection until they are in their late twenties and early thirties.

Those findings, described in a report released yesterday by the United Nations Development Programme (UNDP), can be traced to a variety of causes from social and behavioral factors to anatomy.

According to the study, women between the ages of 15 and 25 make up about 70 percent of the 3,000 women a day who become infected with the AIDS virus and of the 500 women a day who die of AIDS.

In most of the Third World, where AIDS is overwhelmingly a heterosexually transmitted disease, the report said, there are as many female cases as male and sometimes more.

In the United States, women accounted for just 14 percent of AIDS cases last year, but the proportion is growing rapidly. Last week the Centers for Disease Control and Prevention reported that American women of all ages were coming down with AIDS four times as fast as men. In 1992, CDC said, the number of women with AIDS climbed 9.8 percent while the number of men with AIDS grew 2.5 percent.

Also in 1992, heterosexual transmission of

See AIDS, A22, Col. 1

PALL OVER SOUTHERN LEBANON

Smoke billows from a building in Nabatiyah as Israel shelled dozens of villages in south Lebanon for a fourth consecutive day in an offensive intended to halt rocket attacks by The campaign, which has sent hundreds of thousands of Lebanese civilians fleeing nort drew criticism abroad yesterday and expressions of concern from Washington. Story on

AIDS Study Finds Young Women Face Greater Vulnerability

AIDS, From A1

HIV, the AIDS virus, became the leading cause of the disease in women, overtaking the sharing of needles used for intravenous drugs.

A recent study of youths serving in the Job Corps showed that 4.2 women per 100,000 were infected with HIV as compared with 2.4 per 100,000 for men.

"HIV is into the teenage population and it's spreading quickly and silently," said Karen Hein, a specialist in adolescent medicine at the Albert Einstein College of Medicine and director of the adolescent AIDS program at Montefiore Hospital in the Bronx. She said that half of the teenage girls at her clinic who are HIV-positive have had fewer than five sex partners.

"Adolescents are the leading edge of the next wave of the epidemic," said Hein, a consultant to UNDP's effort to examine the impact of AIDS on economic development and a spokeswoman for the study.

The special vulnerability of women was first noted in Africa some years ago, but it was not considered relevant to industrialized countries. In 1986 in Zaire, for example, a study of the first 500 AIDS cases admitted to Kinshasa's Mama Yemo Hospital found as many women as men; but the women averaged 10 years younger.

Still, in those early days of the pandemic, many experts considered African AIDS a different phenomenon from American or European AIDS, which then was overwhelmingly a disease of gay men and intravenous-drug users. The conventional explanation was that Africans had high rates of other sexually transmitted diseases that predisposed them to HIV, especially by causing open sores on the genitals. Another presumed differentiating factor was large numbers of sex partners.

"Things like that led a lot of people to think of AIDS [in the United States] as mainly a gay disease," Hein said. "But things have changed. What people are talking about in Africa is really happening now in this country."

She said American girls are now having sex at younger ages than before, with the median age at first intercourse at 15 to 16. And young people have high rates of other sexually transmitted diseases.

In addition, the UNDP study found, there are factors that put young women at much greater risk than young men.

One is anatomy. The tissue that lines the vagina, and which can be injured during sexual intercourse, is very thin in preadolescent girls. It begins to thicken as puberty progresses and reaches its maximum about two years after the first menstrual period. This factor is most relevant to girls between the ages of 10 and 18. Also increasing during that time is the thickness of vaginal mucus, which exerts several kinds of protective effects.

> ***"HIV is into the teenage population and it's spreading quickly and silently."***
>
> —Karen Hein, Albert Einstein College of Medicine

Yet another factor, which affects women in their later teens and early twenties, involves a special type of cells that ring the opening of the cervix. It is these cells that the human papilloma virus infects to cause cervical cancer and that researchers suspect HIV infects to cause AIDS.

In young women this "transition zone" of cells lies outside the cervical opening, where it is exposed to microbes that enter the vagina. As women mature, the zone moves to a less exposed position inside the opening. Childbirth, however, can move position. As a result, women who give birth at relatively young ages have a higher risk of becoming infected. A study in Rwanda, which lies in the heart of Africa's AIDS region, showed that more than 25 percent of women who became pregnant before age 18 are HIV positive.

By far the most important behavioral factor that makes young females more vulnerable than young males, Hein said, is the low rate of condom use. This is especially significant because girls often have sex with men who are older (and thus more likely to be infected). Boys, on the other hand, tend to have sex with girls their own age. Another factor is that young people have a high rate of anal intercourse. Hein said that 26 percent of the females in a New York City study had practiced anal intercourse, many citing it as a way of preventing pregnancy and maintaining virginity. As in men, the anal tissues are highly susceptible to HIV infection.

In Third World countries, another prominent factor is that when rural people move to the cities, job opportunities for women are even scarcer than for men. As a result, many girls find the only way to support themselves is by selling sex.

In many societies, the youngest women are highly vulnerable to rape, incest and adultery, usually with much older men. Also, access to health care is poor, and predisposing genital diseases go untreated.

"The silence surrounding the infection of young women must be broken," the UNDP report said. "Girls and young women must be able to speak out, to cease to feel silenced or powerless to change what happens to them. Others, too, must speak out."

To remedy the problem, the report urges the development of strategies to lengthen the time before young women are pressured to have sex, to delay the first pregnancy and to increase the ability of girls to control situations in which they have sex, either to avoid it or to insist on condom usage.

For further information call or write:

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92-281 SPR
March 16, 1992

CRS Report for Congress

Congressional Research Service • The Library of Congress

Women With HIV Infection

Judith A. Johnson
Specialist in Life Sciences
Science Policy Research Division

SUMMARY

Although, at present, women account for only 10 percent of AIDS cases reported to CDC, women are the fastest growing group in the HIV epidemic. The route of HIV exposure in women is shifting from IV drug use to heterosexual contact. Because the medical conditions experienced by many HIV-infected women are not included in the CDC AIDS definition, women often are diagnosed and treated later than men. Also, women may not qualify for benefit payments because their symptoms differ from men's.

INTRODUCTION

AIDS is a blood-borne and sexually transmitted disease caused by the human immunodeficiency virus (HIV). HIV compromises the immune system of its victims, rendering them susceptible to infections. The Centers for Disease Control (CDC) estimates that 1 million Americans are infected with HIV. The median time from infection with HIV to diagnosis of AIDS is 10.5 years; 98 percent of HIV-infected individuals will progress to AIDS within 15 to 20 years.[1] The median survival time from AIDS diagnosis to death is about 10 months for heterosexual men and women; the three-year survival rate after a diagnosis of AIDS is approximately 20 percent.[2]

EPIDEMIOLOGY OF WOMEN WITH HIV INFECTION

Through January 1992, more than 209,000 adult and pediatric AIDS cases had been reported to CDC. Of this total, approximately 21,600 were adult and adolescent females; half contracted AIDS through intravenous (IV) drug use and a third through heterosexual contact. The proportion of female AIDS cases connected with IV drug use has been decreasing in recent years while the proportion of such cases attributed to heterosexual contact has been increasing. According to the National Commission on AIDS, over the past several years

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[1]Kolata, G. Studies Cite 10.5 Years from Infection to Illness. New York Times, Nov. 8, 1991. p. B12.

[2]Ellerbrock, T. V., et al. Epidemiology of Women with AIDS in the United States, 1981 Through 1990. New England Journal of Medicine, v. 265, Jun. 12, 1991. p. 2971-2975.

women have been the fastest growing group in the HIV epidemic. Most U.S. women with AIDS are black or Hispanic (73 percent) and live in large metropolitan areas located on the Atlantic coast; however, the proportion of female cases reported from small cities and rural areas has been increasing.[3]

According to CDC, at the present time U.S. women are at higher risk than men of encountering an HIV-infected heterosexual partner since most IV drug users are men, almost all hemophiliacs are men, and some HIV-infected men are bisexual. Also, several studies have indicated that the relative efficiency of transmitting HIV from male to female is greater than from female to male. One study found that women are 17.5 times more likely to acquire HIV from male sexual partners than men are from women.[4] The majority of women diagnosed with AIDS (79 percent) are of reproductive age (15 to 44 years). The incidence of pediatric cases is closely tied to the rate in women since 84 percent of children with AIDS have a mother with or at risk for HIV infection. Researchers estimate that HIV-infected women transmit the virus during pregnancy or delivery to between 25 and 35 percent of their children.[5] Of the estimated 1 million HIV-infected persons in the United States, CDC calculates that 80,000 are women of childbearing age.[6] CDC estimates that, in 1989, approximately 1800 newborns acquired HIV through perinatal transmission, and between 1500 and 2100 babies infected with HIV will be born each year.

While the death rate from other causes has remained relatively stable among American women, between 1985 and 1988, the death rate due to HIV infection increased by a factor of four.[7] In 1991, AIDS became the fifth leading cause of death in U.S. women of reproductive age. In New Jersey and New York, AIDS was the leading cause of mortality in 1987 among black women aged 15 to 44; the HIV/AIDS death rate in this group of women is comparable to the rate occurring in adult women in West Africa.[8]

DEFINITION OF AIDS

The current CDC definition of AIDS was devised in 1981 and revised twice; the last change was adopted in 1987. It requires HIV infection along with

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[3]Ibid., p. 2971.

[4]Padian, N. S., et al. Female-to-Male Transmission of Human Immunodeficiency Virus. Journal of the American Medical Association, v. 266, Sep. 25, 1991, p. 1664-1667.

[5]Ellerbrock, Epidemiology of Women with AIDS, p. 2971.

[6]Gwinn, M., et al. Prevalence of HIV Infection in Childbearing Women in the United States. Journal of the American Medical Association, v. 265, Apr. 3, 1991. p. 1704-1708.

[7]Chu, S. Y., et al. Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age, United States. Journal of the American Medical Association, v. 264, July 11, 1990. p. 225-229.

[8]Ibid., p. 228.

specific opportunistic infections or cancers (such as *Pneumocystis carinii* pneumonia or Kaposi's sarcoma, a skin cancer). The list was developed when AIDS afflicted mainly gay males. In women, the early stages of HIV infection produce different symptoms (such as persistent gynecological infections and cervical cancer) than those in the 1987 CDC definition. Consequently, women are often diagnosed later than men and therefore may miss the opportunity for early treatment which could prolong their lives. Critics of the 1987 CDC AIDS definition have charged that many HIV-infected women die of the disease before they meet the definition and consequently there is a significant underreporting of AIDS cases in women.

In August 1991, CDC proposed a revised surveillance case definition of AIDS. CDC planned to release a final version of the definition in January 1992 and implement the change for reporting AIDS cases early in April 1992. Because of concerns over the potential impact of the definition, CDC has delayed the implementation indefinitely. CDC's proposal would expand the old definition to include HIV-positive people with CD4-lymphocyte counts of less than 200 per milliliter. A CD4-lymphocyte, also called a T4-helper cell, is a type of immune system blood cell which is depleted by HIV infection. CD4 cells aid in the production of disease fighting substances called antibodies; healthy individuals have CD4 counts of about 1000 per milliliter.

Research studies have shown that there is a strong correlation between the development of life-threatening disease in AIDS patients and the level of CD4 cells; as the number of CD4 cells decreases, the risk of developing opportunistic infections and their severity increases. CD4 levels are also being used by physicians as a guide for treatment of HIV-infected people; AZT, an anti-HIV drug, is recommended for those with CD4 counts of less than 500, and treatment to prevent *Pneumocystis carinii* pneumonia is recommended for persons with CD4 counts of less than 200.

CDC estimates that the proposed definition could increase the current AIDS caseload by 150,000 to 200,000.[9] Women's health advocates charge that a significant number of HIV-infected women with serious AIDS-related health problems still will not meet the new case definition. The advocates would prefer adding more women-specific diseases (such as recurrent pelvic inflammatory disease) onto the list. CDC has considered this option but is resisting the idea. The agency believes the list is already too cumbersome for physicians to use (it currently contains more than 20 conditions), and that adding more diseases to the list would make it even more difficult. The National Commission on AIDS has asked CDC to delay implementing the definition so that potential problems posed by the change can be identified and worked out.[10] The Commission is concerned that some HIV-infected women may not be covered by the new definition, and that the CD4 test may not be covered by privacy laws.

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[9]Navarro, M. U.S. Widens Rules on Who Has AIDS. New York Times, Aug. 8, 1991. p. D21.

[10]Change in AIDS Definition May be Delayed. Washington Post, Dec. 11, 1991. p. A9.

The CDC definition as originally developed was intended to be used as an epidemiological tool for tracking the epidemic. However, other Federal, State, and private agencies have in the past relied heavily on CDC's AIDS definition in determining who receives benefits (for example, disability payments, housing and nutrition allowances); those who fit the definition qualified for and received benefits much faster than those who did not qualify and were forced to prove their disability some other way. H.R. 2299, "The Social Security and SSI AIDS Disability Act of 1991," would provide interim disability criteria, including medical conditions specific to women, until a proposed advisory panel's future recommendations on these and other matters become law. A companion bill was introduced in the Senate (S. 1188). No action has occurred on either bill.

In response to pressure from Congress and AIDS health advocates, in December 1991, the Social Security Administration (SSA) proposed new rules which the agency believes should increase the number of HIV-infected people who qualify for SSA benefits. The ability to qualify for Medicare (after a wait of two years) or Medicaid is often contingent upon qualifying for and receiving SSA disability. These health benefits programs assist low-income individuals in paying for AIDS treatments, which can cost $15,000 or more per year. Women's health advocates claim that HIV-infected women have had more difficulty than men in obtaining benefits in the past and probably will continue to have difficulty, even with the proposed rule change.

WOMEN AND AIDS RESEARCH

Women's health advocates have charged that research on AIDS in women has focused primarily on women as vectors of disease transmission to men and infants instead of concentrating on how to treat and prevent the disease in women. Rather than being seen as persons at risk, the advocates claim that women are viewed as risk factors--the sexual partner of an HIV-positive male or the mother of an infected infant. A recent article in the Journal of the American Medical Association provides a factual basis for some of these charges.[11] The authors performed a computer-assisted medical literature review and found that little is known about the progression of HIV-infection in women, and that few studies have been performed to clarify this situation. Conditions specific to women (such as cervical disease, and vaginal yeast infections) seem to be more serious in HIV-infected women. The manner in which drugs are absorbed and metabolized may also vary with gender, and the use of oral contraceptives may alter drug metabolism.

In addition, the authors point out that most women with HIV differ from the risk groups first affected by AIDS, not only in gender, but also in race, income, and risk behaviors. "These factors combine to yield an amalgam of social barriers to optimal care....[Women] are also subject to discrimination on the basis of gender or childbearing capacity when they attempt to gain access

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[11]Minkoff, H.L., and J.A. DeHovitz. Care of Women Infected with the Human Immunodeficiency Virus. Journal of the American Medical Association, v. 266, Oct. 23/30, 1991. p. 2253-2258.

to drug rehabilitation, HIV therapeutics, and research trials....These realities, along with the demographic characteristics of HIV-infected women (often poor and from racial/ethnic minority groups), have created a seriously disenfranchised and medically disadvantaged population."[12]

There are a number of reasons why women often are underrepresented in clinical trials of AIDS drugs: (1) they may be excluded because they are women and are either potentially or actually pregnant; (2) they are members of minority groups and lack access to the health care system in general, and to research in particular; (3) they are drug users and are presumed to be noncompliant subjects; and (4) most of the trials so far have focused on AIDS itself, and many women do not fit the clinical definition of AIDS.[13] On the issue of pregnancy, the regulatory system views fetuses as defenseless subjects in need of special risk protection, and pharmaceutical companies seek to avoid potential liability for the possible adverse effects experimental drugs may have on the unborn.

The exclusion of women from clinical trials has been general practice in all areas of medical research, not just AIDS. There are those who argue that it may, however, be short-sighted for our society to allow this practice to continue. "A policy that excludes women from research but then exposes them to risks--unknown because unstudied--through the more haphazard route of medical practice, fails to protect their interests in obtaining the safest and most effective therapies....Without scientific evidence to guide them, physicians are left to improvise on dosages and choices of drugs."[14] The Public Health Service (PHS) has recognized this situation as a serious impediment to improving the health of American women. In response to this and other factors inhibiting the advancement of women's health, the agency has developed the "PHS Action Plan for Women's Health," which was published in September 1991. In the "Action Plan," the sections describing the efforts of the Food and Drug Administration, the National Institutes of Health (NIH), and the Alcohol, Drug Abuse and Mental Health Administration specifically identify the importance of including women in clinical trials as major objectives for their women's health programs.

A 1990 General Accounting Office (GAO) report found that NIH had scarcely implemented its 1986 policy to include more women in its research studies. Following release of the GAO report, Representative Patricia Schroeder introduced "The Clinical Trials Fairness Act" (H.R. 1160), which would require that women and minorities be included in clinical research conducted under the PHS Act. H.R. 1160 is also included in "The Women's Health Equity Act," (H.R. 1161); no action has been taken on these bills. However, a similar provision was contained in NIH reauthorization legislation (H.R. 2507) passed by the House in July 1991. The Senate's NIH reauthorization bill (S. 1523) is likely to receive

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[12]Ibid., p. 2257.

[13]Levine, C. Women and HIV/AIDS Research: The Barriers to Equity. IRB, Jan./Apr. 1991, p. 18-22.

[14]Ibid., p. 20.

floor action in the second session.[15] In August 1991, NIH published a reiteration and further interpretation of its policy concerning inclusion of women in research study populations.

PHS sponsored the first National Conference on Women and HIV Infection in December 1990. Following the conference, a core group of participants developed recommendations for further research. They found that increased attention needs to be focused on psychosocial and behavioral as well as biomedical research. This will require greater collaboration between government agencies, research facilities, and community groups. The recommendations will be used by PHS agencies in planning programs and research on women with AIDS. The NIH AIDS Program Advisory Committee, which advises the NIH leadership on AIDS issues, urged the implementation of the recommendations.

A number of NIH components including the National Institute of Allergy and Infectious Diseases (NIAID), the National Institute of Child Health and Human Development, and the National Cancer Institute, have joined with CDC to form the PHS Women and AIDS Study Group. "This group will review questions that need to be addressed on the natural history of HIV infection in women. In addition, the group will work toward the design of a core dataset for women's studies, to be shared among PHS agencies, to aid in the interpretation of findings from different studies."[16] NIAID's AIDS Clinical Trial Group has formed a new committee, the Women's Health Committee, to address the growing need for research on HIV-infected women.

The Agency for Health Care Policy and Research is sponsoring a panel of health care experts and consumers to develop HIV clinical practice guidelines that address the unique needs of specific population groups, including HIV-infected women. After the guidelines have been drafted and peer reviewed, a pilot test will be conducted for usability at a cross-section of health provider sites. When completed, the guidelines will be widely disseminated to practitioners, patients, medical educators, and consumers.

Women and AIDS Research
($ Millions; data, NIH 3/6/92)

FY90 Actual	FY91 Actual	FY92 Estimate	FY93 Request
$68.2	$97.4	$104.9	$119.0

[15]Other bills introduced in the 102nd Congress which target women with AIDS include "The Women and AIDS Outreach and Prevention Act," (H.R. 1072), and "The Women and AIDS Research Initiative Amendments of 1991," (H.R. 1073); both measures are included in H.R. 1161.

[16]APAC Endorses Research Plan for Women and HIV Infection. NIAID AIDS Agenda, Summer 1991. p.1-5.

I

103D CONGRESS
1ST SESSION

H. R. 2394

To amend the Public Health Service Act to establish programs of research with respect to women and cases of infection with the human immunodeficiency virus.

IN THE HOUSE OF REPRESENTATIVES

JUNE 10, 1993

Mrs. MORELLA (for herself, Mr. BIELENSON, Mr. FRANK of Massachusetts, Mr. FROST, Mr. GIBBONS, Mr. GILMAN, Mr. JEFFERSON, Ms. EDDIE BERNICE JOHNSON of Texas, Mr. MATSUI, Mr. MCDERMOTT, Mrs. MEEK, Mr. MILLER of California, Mrs. MINK, Ms. MOLINARI, Ms. NORTON, Mr. PAYNE of New Jersey, Mr. SANDERS, Mrs. SCHROEDER, Ms. SNOWE, Mr. STUDDS, Mr. TOWNS, Mrs. UNSOELD, Ms. WATERS, Mr. WHEAT, Mr. WYDEN, and Mr. YATES) introduced the following bill; which was referred to the Committee on Energy and Commerce

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A BILL

To amend the Public Health Service Act to establish programs of research with respect to women and cases of infection with the human immunodeficiency virus.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Women and AIDS Research Initiative Amendments of 1993".

SEC. 2. ESTABLISHMENT OF GENERAL PROGRAM OF RESEARCH REGARDING WOMEN AND ACQUIRED IMMUNE DEFICIENCY SYNDROME.

Part B of title XXIII of the Public Health Service Act (42 U.S.C. 300cc–11 et seq.) is amended by adding at the end the following section:

"SEC. 2321. RESEARCH REGARDING WOMEN.

"(a) IN GENERAL.—With respect to cases of infection with the human immunodeficiency virus, the Secretary shall establish a program for the purpose of conducting biomedical and behavioral research on such cases in women, including research on the prevention of such cases. The Secretary may conduct such research directly, and may make grants to public and nonprofit private entities for the conduct of the research.

"(b) CERTAIN FORMS OF RESEARCH.—In carrying out subsection (a), the Secretary shall provide for research on—

"(1) the manner in which the human immunodeficiency virus is transmitted to women, including the relationship between cases of infection with such virus and other cases of sexually transmitted diseases, including clinical trials which examine the question of how much human immunodeficiency virus infection can be prevented by finding and treating sexually transmitted diseases in women;

"(2) measures for the prevention of exposure to and the transmission of such virus, including research on—

"(A) the prevention of any sexually transmitted disease that may facilitate the transmission of the virus;

"(B) rapid, inexpensive, easy-to-use sexually transmitted disease diagnostic tests for women;

"(C) inexpensive single dose therapy for treatable sexually transmitted diseases;

"(D) the development of methods of prevention for use by women; and

"(E) the development and dissemination of prevention programs and materials whose purpose is to reduce the incidence of substance abuse among women;

"(3) the development and progression of symptoms resulting from infection with such virus, including research regarding gynecological infections as well as breast changes, hormonal changes, and menses and menopause changes, whose occurrence becomes probable as a result of the deterioration of the immune system;

"(4) the treatment of cases of such infection, including clinical research: and

"(5) behavioral research on the prevention of such cases and research on model educational programs for such prevention.

"(c) CLINICAL TRIALS.—

"(1) GYNECOLOGICAL EVALUATIONS.—In clinical trials regarding the human immunodeficiency virus in which women participate as subjects, the Secretary shall ensure that—

"(A) each female subject who is infected with the human immunodeficiency virus—

"(i) undergoes a gynecological examination as part of the evaluation of the medical status of the woman prior to participation in the trial; and

"(ii) receives appropriate follow-up services regarding such examination; and

"(B) the results of the gynecological examinations are analyzed to determine the relationship between gynecological conditions and the infection with such virus.

"(2) STANDARD TREATMENTS FOR GYNECOLOGICAL CONDITIONS.—The Secretary shall conduct or support clinical trials under subsection (a) to de-

termine whether standard methods of treating gynecological conditions are effective in the case of such conditions that arise as a result of infection with the human immunodeficiency virus.

"(3) EFFECTIVENESS OF CERTAIN TREATMENT PROTOCOLS.—With respect to cases of infection with the human immunodeficiency virus, the Secretary shall conduct or support clinical trials under subsection (a) to determine whether treatment protocols approved for men with such cases are effective for women with such cases.

"(4) SUPPORT SERVICES.—

"(A) In conducting or supporting clinical trials regarding the human immunodeficiency virus in which women participate as subjects, the Secretary shall provide the women with such transportation, child care, and other support services (including medical and mental health services, treatment for drug abuse, and social services, including services addressing domestic violence) as may be necessary to enable the women to participate as such subjects.

"(B) Services under subparagraph (A) shall include services designed to respond to the particular needs of women with respect to par-

ticipation in the clinical trials involved, including, as appropriate, training of the individuals who conduct the trials.

"(d) PREVENTION PROGRAMS.—

"(1) SEXUAL TRANSMISSION.—

"(A) With respect to preventing the sexual transmission of the human immunodeficiency virus, the Secretary shall conduct or support research under subsection (a) on barrier methods for prevention of sexually transmitted diseases, including human immunodeficiency virus disease, that women can use without their sexual partner's cooperation or knowledge.

"(B) In carrying out subparagraph (A), the Secretary shall give priority to identified research needs and opportunities identified at the National Institutes of Health sponsored meeting on Development of Topical Microbicides held in May 1993, including research on—

"(i) the early steps in infectious processes;

"(ii) identification, formulation, and preclinical evaluation of new preparations;

"(iii) clinical testing for safety and efficacy; and

"(iv) studies on acceptability and compliance of safe, effective microbicides.

"(2) EPIDEMIOLOGICAL RESEARCH.—The Secretary shall conduct or support epidemiological research under subsection (a) to determine the factors of risk regarding infection with the human immunodeficiency virus that are particular to women, including research regarding—

"(A) the use of various contraceptive methods;

"(B) the use of tampons;

"(C) the relationship between such infection and other sexually transmitted diseases;

"(D) the relationship between such infection and various forms of substance abuse (including use of the form of cocaine commonly known as crack); and

"(E) the relationship between such infection and noncoital forms of sexual activity.

"(e) INTERAGENCY STUDY.—With respect to the study (known as the Women's Interagency HIV Study) that, as of June 1993, is being carried out by the Secretary through various agencies of the Public Health Service for the purpose of monitoring the progression in women of infection with the human immunodeficiency

virus, and determining whether such progression is different in women than in men, the following applies:

"(1) The Secretary shall ensure that not less than 5,000 women with such infection are included in the study.

"(2) The Secretary shall provide for an increase in the number of sites at which the study is to be conducted.

"(3) The Secretary shall ensure that the study period is for a minimum of 8 years.

"(4) With respect to markers of human immunodeficiency virus disease progression and viral activity, including the cells commonly known as CD4 cells, the Secretary shall ensure that the study adequately addresses the relationship between such markers and the development of serious illnesses in such women, including the relationship between the number of such cells and the development of such illnesses. For purposes of the preceding sentence, the study shall address gynecological conditions, and other conditions particular to women, that are not currently included in the list of conditions arising from such infection that, for surveillance purposes, is maintained by the Director of the Centers for Disease Control and Prevention.

"(f) DEFINITIONS.—For purposes of this section, the term 'human immunodeficiency virus' means the etiologic agent for acquired immune deficiency syndrome.

"(g) AUTHORIZATIONS OF APPROPRIATIONS.—

"(1) CLINICAL TRIALS.—

"(A) For the purpose of carrying out subsection (c)(1), there are authorized to be appropriated $20,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 through 1996.

"(B) For the purpose of carrying out subsection (c)(2), there are authorized to be appropriated $10,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 through 1996.

"(C) For the purpose of carrying out subsection (c)(3), there are authorized to be appropriated $10,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 through 1996.

"(D) For the purpose of carrying out subsection (c)(4), there are authorized to be appropriated $15,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 and 1996.

"(2) PREVENTION PROGRAMS.—

"(A) For the purpose of carrying out subsection (d)(1), there are authorized to be appropriated $30,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 through 1996.

"(B) For the purpose of carrying out subsection (d)(2), there are authorized to be appropriated $10,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 through 1996.

"(3) INTERAGENCY STUDY.—For the purpose of carrying out subsection (e), there are authorized to be appropriated $15,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 through 1996.".

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WOMEN OF COLOR LEADERSHIP FORUM

September 1, 1993

Ms. Kristine M. Gebbie
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Hubert H. Humphrey Building
200 Independence Avenue
Room 73-8G
Washington, D.C. 20203

Dear Ms. Gebbie:

It has come to the attention of the Women of Color Leadership Forum that a meeting has been scheduled for September 7, 1993 to brief you, and on September 13, 1993, a congressional delegation, concerning the issue of HIV/AIDS as it infects and affects women in this pandemic.

We understand that, as of July 1, 1993, the CDC HIV/AIDS Surveillance Report shows a cumulative total of 36,690 women with AIDS. Of this number, Black, Hispanic, Asian/Pacific Islander, American Indian/Alaska Native total 27,289 with White women totaling 9,330. Additionally, 2,401 of the 4,462 cases of children with AIDS, come from the cities of New York, the greater Miami, Florida area (Miami, West Palm Beach, Fort Lauderdale), Newark, New Jersey, Chicago, Illinois, Los Angeles, California, Baltimore, Maryland, Washington, D.C. and Boston, Massachusets. 243 children in Puerto Rico have AIDS.

To our knowledge, the planning process for these meetings has excluded adequate diverse representation of women of color. In particular, women of color, self-identified as living with HIV have not been invited to actively participate in the entire process. This is unacceptable.

We, the Women of Color Leadership Forum, perceive this exclusion to be disempowering; the implication is that we are unable to speak for ourselves about a matter that is crucial to our very existence. We, therefore, propose the following:

- That the scheduled meeting as currently constituted be cancelled.
- That a new meeting date be scheduled to enable our group to develop a diverse representation of women of color to meet with you.

OFFICE OF THE NATIONAL AIDS POLICY COORDINATOR

EXECUTIVE OFFICE OF THE PRESIDENT
750 17th Street, N.W. Suite 1060
Washington, D.C. 20500

Phone: (202) 632-1090
Fax: (202) 632-1096

DELIVER TO: Cheryl

SENT FROM: Sandy Bart

Number of Pages: 1+ cover Fax Number: (202) 544-0378

Date: 9/3/93

Message: Per our telephone conversation, please review the attached list and make any necessary corrections. Also, as we discussed, I will need mailing addresses for the names of individuals who are circled. If you could let me know if my additions to the names (Ms., Mr., Dr.) are correct, please call me at 202-690-5560 and I can send out the original letter from Ms. Gebbie. I will need the mailing addresses as soon as possible so that copies can be mailed to each individual listed. Thanks for your help.

cc: Donna Shalala, PhD., Secretary for Health and Human Services;
Phillip Lee, M.D., Assistant Secretary for Health;
Jocelyn Elders, M.D.;
Jo Ivey Bufford, M.D., Office of the Assistant Secretary for Health;
Audrey Manley, M.D., Office of the Assistant Secretary for Health;
Patsy Fleming, Special Assistant to the Secretary for Health and Human Services;
Sarah Kovner, Special Assistant to the Secretary for Health and Human Services;
Ms. Michelle Wilson, Director of the Positive Woman;
Dr. Vicki Mays, PhD. U.C.L.A.;
Ms. Nancy Heinrich;
Ms. Leslie Wolfe;
Dr. Steve Morin;
Ms. Cindy Hall;
Ms. Kelly O'Brien;
Ms. Constance Miller;
Elena Alvarado;
Buck Buckingham;
Mst. Jennifer Chambers;
Ms. Toni Young.

cc: Donna Shalala, PhD., Secretary for Health and Human Services;
Phillip Lee, M.D., Assistant Secretary for Health;
Jocelyn Elders, M.D.;
Jo Ivey Bufford, M.D., Office of the Assistant Secretary for Health;
Audrey Manley, M.D., Office of the Assistant Secretary for Health;
Patsy Fleming, Special Assistant to the Secretary for Health and Human Services;
Sarah Kovner, Special Assistant to the Secretary for Health and Human Services;
Michelle Wilson, Director of the Positive Woman;
Vicki Mays, PhD. U.C.L.A.;
Nancy Heinrich;
Leslie Wolfe;
Steve Morin;
Cindy Hall;
Kelly O'Brien;
Constance Miller;
Elena Alvarado;
Buck Buckingham;
Jennifer Chambers;
Toni Young.

Any other meeting that purports to develop and design an agenda to address the complex issues of women and AIDS without our leadership would be insensitive, inadvisable and inappropriate. The issues of women and HIV/AIDS where over 74% of the women living with AIDS are women of color, can be neglected no longer. We look forward to working with you and we will call your office to set up a meeting.

Sincerely,

Charon Asetoyer, Executive Director
Native. Am. Women's Hlth. Ed. Resource Center

Luz Martinez, Director
National Latina Health Organization

Dazon Dixon, Executive Director
Sister Love, Incorporated.

Pandora Singleton, Coordinator
Azuka

Norma Baker, Executive Director
Northern Educational Service, Inc.

Barbara Gomes-Beach, Executive Director
Multicultural AIDS Coalition, Inc.

Jacquelyn Wilkerson, Director
AIDS Advocacy/African Am. Churches

Miguelina Maldonado, Executive Director
Hispanic AIDS Forum

Teresa Chief Eagle, Native American
Women's Health Ed. Res. Center

Zaida Castillo

Mary Chung, Executive Director
API For Reproductive Health

Deborah Thomas

Charlene Doria-Ortiz, Interim Dir.
Center for Health Policy Dev.

Patricia Griffin
Ashanti Project

Suki Terada Ports, Director
Family Health Project

Ellarwee Caddoden, Executive Director
Women, Inc.

Gayle L. Terry
National Minority AIDS Council

Vivian Torres, Coordinator
Vivian's Place

Marie St. Cyr-Dolpe, Director
Iris House, Incorporated.

Yvette C. Burton

THE WHITE HOUSE

WASHINGTON

September 2, 1993

Mrs. Dorothy Haddox
3209 Susan Circle
Youngstown, Ohio 44511

Dear Mrs. Haddox:

Thank you for writing, and the good wishes. I am flattered you ask, but am sorry to say I have no autographed pictures.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

September 2, 1993

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3209 Susan Circle
Youngstown, Ohio 44511

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Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Prepared by: APO: TFox: 9/9/93:202-690-5560:b:\foxlts.gbe\haddox.gbe

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

sorry no
picture

MRS. DOROTHY HADDOX
3209 Susan Circle
Youngstown, Ohio 44511

YOUNGSTOWN, OH 44 PM Aug 14 1993

ALWAYS USE ZIP CO

29 USA

Please forward

Kristine Gebbie
Aids Czar
White House
Washington D C

AUG 14 1993

Miss Gebbie

Would love to have your autographed picture for my collection of famous women.

Wishing you the best for the coming years.

Thank you

Dorothy Haddox

MRS. DOROTHY HADDOX
3209 Susan Circle
Youngstown, Ohio 44511

THE WHITE HOUSE

WASHINGTON

September 2, 1993

Ms. Patricia C. Gorton
3853 Ingraham C-316
San Diego, California 92109

Dear Ms. Gorton:

Thank you for writing and sharing your concerns about the transmission of the human immunodeficiency virus (HIV).

Although I am not aware of research involving the transmission of HIV via saliva in swimming pools, overwhelming evidence indicates that this would be a highly unlikely mode of transmission. Studies designed to test transmission of HIV through saliva have demonstrated that it does not occur.

If you would like information on HIV research, please write to the:

Office of AIDS Research
National Institutes of Health
NIH Building 1, Room 201
9000 Rockville Pike
Bethesda, Maryland 20892

Office for HIV/AIDS
Centers for Disease Control and Prevention
Executive Park Building
1600 Clifton Road, N.E.
Mail Stop - D21
Atlanta, Georgia 30333

While I support widespread HIV antibody testing as a part of our national effort to limit the spread of HIV, I do not think mandatory testing is appropriate. We must, however, continue consideration of any appropriate actions.

Again, thank you for sharing your thoughts with me.

Sincerely,

Kristine M. Gebbie, RN, MN

THE WHITE HOUSE

WASHINGTON

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San Diego, California 92109

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National AIDS Policy Coordinator

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draft
reply - 1

Ms. Kristine Gebbie, "AIDS Czar"
c/o The White House
1600 Pennsylvania Ave., N.W.
Washington, D.C. 20500

Dear Ms. Gebbie:

I was pleased to see in the recent Newsweek article that you intend to combat the spread of AIDS. One way would be to conduct more research on ways in which it may be communicated.

The literature is starting to document ways of transmission other than through the four specific ways that the CDC cites. It transmits in saliva*. Can chlorine kill the AIDS virus in saliva or is it possible to contract HIV in public swimming pools? If, as the CDC states, the mucous membrances of the eye, nose, and mouth should be considered as potential pathways for entry of virus**, how can we be sure that it doesn't spread in swimming pools unless research has been conducted to specifically test for that?

If no research has been conducted in this regard, isn't it time that there should be? Millions of Americans use public swimming pools, and we have no idea whether or not they are safe.

Thank you for your attention to this matter which may be (without research, we don't know) of life and death significance to millions of Americans.

Also, because of the risk incurred by health care workers who are serving HIV and AIDS patients, it would make sense to require testing of patients prior to surgery where the health care workers might be infected. If people quit going into medicine and nursing because of our failure to protect them from HIV/AIDS, the country will face a healthcare emergency as we haven't yet dreamed about.

You are to be commended for taking on the challenges of your office.

Sincerely,

Patricia C. Gorton

Patricia C. Gorton

Pat and Dick Gorton
3853 Ingraham C-316
San Diego, CA 92109

Ms. Kristine Gebbie,
"AIDS Czar"
c/o The White House
1600 Pennsylvania Ave., N.W.
Washington, D.C. 20500

THE WHITE HOUSE

WASHINGTON

September 2, 1993

Mr. Deon Colby
Boone Jr.-Sr. High School
500 7th Street
Boone, Iowa 50036

Dear Mr. Colby:

Your request for the HIV/AIDS information has been sent to the Centers for Disease Control and Prevention's (CDC) National AIDS Clearinghouse. They will send you a catalog describing the posters and brochures that they have available in bulk or individually. For further information or future requests, the number for the Clearinghouse is 1-800-458-5231.

I am pleased that you are striving to increase the awareness of your students about HIV/AIDS. As we continue our fight against this disease, individuals such as you are an essential part of the effort to get accurate, unbiased information to our youth.

Thank you for writing and best wishes.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

cc: NAIC

THE WHITE HOUSE

WASHINGTON

September 2, 1993

Mr. Deon Colby
Boone Jr.-Sr. High School
500 7th Street
Boone, Iowa 50036

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Thank you for writing and best wishes.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

cc: NAIC

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OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

I called the Clearinghouse on 9/2 & they will send him a catalog.

August 19, 1993

AIDS Coordinator
U.S. Public Health Service
Washington. D.C. 20201

Deploy & note that we've asked clearinghouse to send them info

Dear Sir.

In preparation of classes that I teach in the Home Economics Dept at Boone High School (Health. Child Development. Human Growth & Foods) I am interested in the resources that you have available that might be beneficial in the teaching of HIV/AIDS awareness.

Any available leaflets, pamphlets. posters suitable for high school level would be most appreciated.

Thank You - Hope to be hearing from you shortly.

Sincerely

DeDe Colby
Boone Jr-Sr. High School
500 7th St.
Boone. IA 50036

DeOn Colby
Boone Jr. - Sr. High School
500 7th St.
Boone, IA 50036

AIDS COORDINATOR
U.S. Public Health Service
National AIDS Program
Hubert Humphrey Bldg.
Room 738-6
200 Independence Ave. S.W.
Washington D.C. 20201

THE WHITE HOUSE

WASHINGTON

September 2, 1993

Ms. Margaret Pruitt Clark, Ph.D.
President
The Center for Population Options
1025 Vermont Avenue, N.W.
Suite 210
Washington, D.C. 20005

Dear Dr. Clark:

Thank you for writing, and sharing information regarding adolescent health. Our young are indeed an important, vulnerable population.

I agree that prevention programs are key to mounting an effective response to the HIV epidemic. Prevention will be a major part of my agenda as the National AIDS Policy Coordinator. Accomplishing prevention will take many activities to both educate individuals and support them in a lifetime of wise behavior choices.

I appreciate your offer of assistance and that of Ms. Haughton-Dennis.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

September 2, 1993

Ms. Pamela Haughton-Denniston
Director of Public Affairs
The Center for Population Options
1025 Vermont Avenue, N.W.
Suite 210
Washington, D.C. 20005

Dear Ms. Haughton-Denniston:

Thank you for writing, and sharing information regarding adolescent health. Our young are indeed an important, vulnerable population.

I agree that prevention programs are key to mounting an effective response to the HIV epidemic. Prevention will be a major part of my agenda as the National AIDS Policy Coordinator. Accomplishing prevention will take many activities to both educate individuals and support them in a lifetime of wise behavior choices.

I appreciate your offer of assistance and that of Dr. Clarke.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

September 2, 1993

Ms. Margaret Pruitt Clark, Ph.D.
President
The Center for Population Options
1025 Vermont Avenue, N.W.
Suite 210
Washington, D.C. 20005

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Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Prepared by: APO: TFox: 9/1/93:202-690-5560:b:\foxlts.gbe\clark.gbe

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OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

ADOLESCENT REPRODUCTIVE HEALTH

the Center for Population Options

CPO works to increase the opportunities and abilities of youth to make healthy decisions about sexuality.

Adolescent Reproductive Health Policy:
Comprehensive Sexuality Education
Reproductive Health Care, including abortion
School-Based and School-Linked Health Centers
Teen Pregnancy Prevention
HIV/STD Prevention
Peer Programs

(202) 347-5700
FAX (202) 347-2263
The Center for
Population Options
1025 Vermont Ave, NW
Suite 210
Washington, DC 20005

Margaret Pruitt Clark, Ph.D.
President
Pamela Haughton-Denniston
Director of Public Affairs

the Center for Population Options

August 18, 1993

Ms. Kristine Gebbie
Nat'l AIDS Policy Coordinator
Hubert H. Humphrey Building
200 Independence Ave., SW
Rm 738G
Washington, DC 20201

Dear Ms. Gebbie:

As you are probably all too aware, statistics on teen health and sexual risk-taking behaviors are staggering. For example, rates of teen pregnancy are rising again. The Center for Population Options (CPO) estimates that, in 1991, families begun by teen mothers cost the federal government alone $29.28 billion through the Aid to Families with Dependent Children, Medicaid and Food Stamp programs. In addition, the rates of sexually-transmitted disease including HIV among teens remind us of the increasing threat these infections pose to our young people's health.

Sexual risk-taking behavior is highly correlated with other types of risky behaviors, such as substance abuse, delinquency and violence. The federal government has the opportunity to confront these issues by adopting policies and practices which encourage services to protect the health of adolescents.

The commitment of the Clinton Administration to prevention is encouraging. Agencies and individuals working in the areas of substance abuse, reproductive health, justice, education and job training will play a critical role in collaborating to find solutions to these complex problems.

Efforts over the past few decades have established prevention programs that work, if they are fully implemented and supported. The enclosed materials provide background information on the crisis in adolescent reproductive health as well as a series of policy recommendations aimed at prevention.

The Center for Population Options is the only national organization dedicated to improving the opportunities for,

Margaret Pruitt Clark, Ph.D.
Executive Director
1025 Vermont Avenue, N.W.
Suite 210
Washington, D.C. 20005 USA
202/347-5700
FAX 202/347-2263

and abilities of, young people to make healthy decisions about their sexuality. Recognizing the difficulty in mobilizing support for efforts aimed at these issues, CPO is happy to provide information or other support to you or your staff regarding these important adolescent health concerns.

Sincerely,

Margaret Pruitt Clark

Margaret Pruitt Clark, Ph.D.
President

Pam Haughton-Denniston

Pamela Haughton-Denniston
Director of Public Affairs

THE WHITE HOUSE

WASHINGTON

September 3, 1993

Mr. Rocky Parfait
Area Community Care, Educational
Social Support (ACCESS)
301 North Cameron
Victoria, Texas 77901

Dear Mr. Parfait:

Thank you for taking the time during the recent San Antonio HIV/AIDS meeting to meet with me. I appreciated the opportunity to spend a while hearing from you and your colleagues what is and is not working at the local level in the Southwest.

Please stay in touch, sharing with me any specific ideas, examples or issues which you think may help me do my job better. My best wishes to you in your continuing efforts.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

September 3, 1993

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301 North Cameron
Victoria, Texas 77901

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Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Prepared by: APO: KMGebbie: gw: 9/2/93: 632-1090: b:\parfait

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OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

THE WHITE HOUSE

WASHINGTON

September 3, 1993

Mr. Robert Falletti
1902 Park
Houston, Texas 77019

Dear Mr. Falletti:

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Please stay in touch, sharing with me any specific ideas, examples or issues which you think may help me do my job better. My best wishes to you in your continuing efforts.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

September 7, 1993

Mr. Robert Falletti
1902 Park
Houston, Texas 77019

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My best wishes to you in your continuing efforts.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Prepared by: APO: KMGebbie: gw: 9/7/93: 632-1090: b:\falletti

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

THE WHITE HOUSE

WASHINGTON

September 3, 1993

Mr. Robert L. Helmer
Executive Vice President
Hunter Medical, Inc.
2104-A Gallows Road
Vienna, Virginia 22182

Dear Mr. Helmer:

I appreciated the chance to learn a little about Hunter Medical, and to meet Dr. Harris.

Best wishes to you in your endeavors. Please keep me posted as your plans for an AIDS-related conference go forward.

Sincerely,

Kristine Gebbie /c

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Dear Mr Helmer —

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Sue.