FOIA Number: 2018-0756-F

FOIA MARKER

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Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member: Kristine Gebbie

Subseries:

OA/ID Number: 8301

FolderID:

Folder Title:
San Francisco AIDS Foundation [Folder 2]

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

Clinton Presidential Records

Graphic/Offensive Material Marker

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PLEASE READ BEFORE PROCEEDING INTO FOLDER

SAN FRANCISCO AIDS FOUNDATION

DAVE FORD
Media Relations Manager
Main: 415/864-5855, ext. 3031
Direct: 415/487-3031
FAX: 415/487-3098

Office address: 1170 Market St., 6th Fl., San Francisco, CA 94102
Mailing address: P.O. Box 426182, San Francisco, CA 94142-6182

Retina —

I'm pretty sure I did do a thank you to SF Aids fdn —

can you check?

Thanks!

Kristine

6/27/94

You sent them a thank you note via Lance Henderson dated 6/8/94.

Retina

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Digital Records Marker

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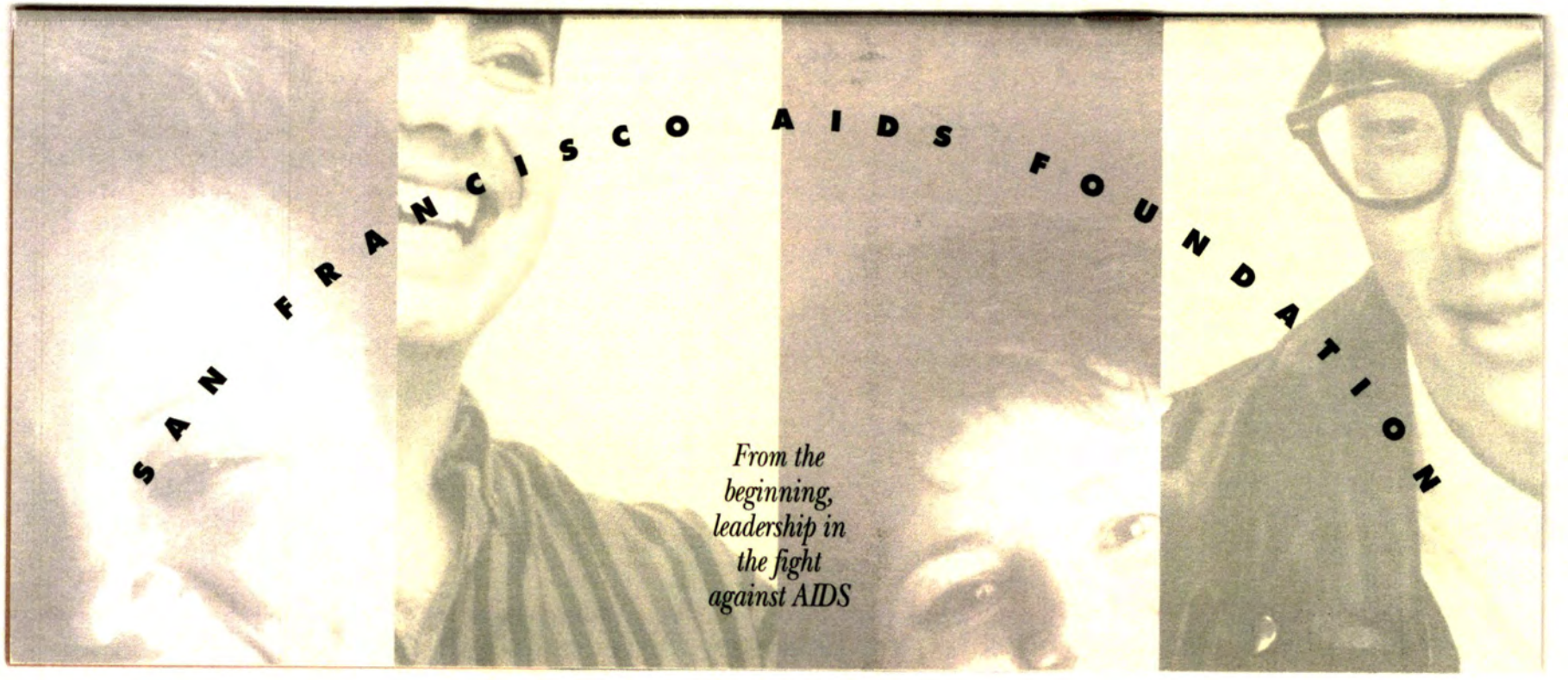
San Francisco AIDS
Foundation

12pgs


SAN FRANCISCO AIDS FOUNDATION
From the beginning, leadership in the fight against AIDS

Printed on Recycled Paper DESIGN: Emil Yanos Design

COMPASS PROJECT

a free personalized service for all gay and bisexual men concerned about HIV

DIRECTION

- support
- planning
- referral
- follow-up

SF AIDS FOUNDATION

San Francisco AIDS Foundation
Compass Project
25 Van Ness Avenue, Suite 700
(415) 864-0968

Phone-in Hours:
11 am - 7 pm M•T•Th•F
11 am - 3 pm Sat

Drop-in Hours:
11 am - 1 pm
5 - 7 pm M•T•Th•F

Closed on Wednesdays and Sundays

The COMPASS PROJECT *helps gay or bisexual men cope with the HIV epidemic. Our services include telephone support, drop-in support, or individual office appointments, with follow-up contact. We offer direction and assistance through step-by-step planning and referral that addresses 4 key areas:*

- *Safe sex*
- *Questions about HIV testing or retesting*
- *HIV emotional impact*
- *Early care for HIV*

The HIV epidemic is a daily challenge. Whether you do not know your HIV status, are HIV negative, or HIV positive, you face difficult and important choices. It's not always easy and sometimes it would help to have some direction in coping with your problems.

At the COMPASS PROJECT you can talk with us once or several times until your needs are met. We can help you learn about safe sex and how to stay safe or assist you in deciding which local services might be suitable and how to find them. We can also help you learn more about early care options and how to better cope with your health issues or feelings.

The COMPASS PROJECT welcomes your phone call or drop-in visit. All services are free and completely confidential. Bilingual services are also available. Servicios disponibles en Español.

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

SAN FRANCISCO AIDS FOUNDATION
Purpose and Missions

The purpose of the San Francisco AIDS Foundation is to hasten the end of the HIV epidemic and to mitigate its impact on society. In response to the epidemic, the Foundation has the following mission:

- Educate the public to prevent the transmission of HIV; help individuals make informed choices about HIV-related concerns; and assure the protection of the human rights of all those affected by HIV disease.

- Provide and support designated client services for those in San Francisco affected by HIV disease.

- In cooperation with other agencies, provide leadership to create innovative, non-duplicative, educational programs, direct services, and public policy initiatives.

- Initiate and support public policies that further these goals.

PROGRAM AREAS

Education

- Trilingual (English/Spanish/Filipino) AIDS Hotline • *Positive News* (lower-literacy newsletter for people with HIV, published in Chinese, English, Spanish, and Filipino) • *BETA* (Bulletin of Experimental Treatments for AIDS) • The Compass Project (personalized case management services for gay/bisexual men with concerns about HIV)

Client Services

- Case Management Services, including special needs of women, gay and bisexual men, those facing addiction or mental health issues, and people of diverse racial, ethnic and cultural groups, including monolingual Spanish-speaking clients • Emergency Housing • Financial Benefits Advocacy

Public Policy

- Advocating for: Increased funding for AIDS treatment, care, and prevention/education at the local, state, and federal levels, including full funding of the Ryan White CARE Act; state-sanctioned needle exchange; antidiscrimination protection for people with HIV/AIDS; federal and state HIV prevention reform • BAHAN (Bay Area HIV Advocacy Network) working to increase grassroots involvement and organizing capacity throughout the 11-county Bay Area

Communications

- Media response and publicity • Prevention campaigns targeting: Gay and bisexual men of all colors, including gay youth; women; injection drug users and their partners; people who are HIV+ (Early Care and Treatment)

25 VAN NESS AVENUE, SUITE 660 / 1170 MARKET STREET, 5TH FLOOR
SAN FRANCISCO, CALIFORNIA 94102
(415) 864-5855

AIDS STATISTICAL FACT SHEET

International

As of January 1, 1994...

- The World Health Organization estimates there are 3 million AIDS cases worldwide. Over 850,000 have died as a result.
- 15 million people are estimated to be infected with HIV, the virus that causes AIDS. Over 40% of those individuals are women.

National

As of December 31, 1993...

- According to the Centers for Disease Control and Prevention, 361,509 people have been diagnosed with AIDS.
- The first 100,000 cases of AIDS were diagnosed in the first 8 years of the epidemic; the next 100,000 were diagnosed in just 26 months; the third 100,000 were diagnosed in 18 months.
- It is estimated that 1-1.5 million Americans are infected with HIV.
- 220,871 Americans have died of AIDS, nearly four times the number of Americans who died in the Vietnam War (58,721).
- AIDS is leading cause of death among American men aged 25-44, and the 4th leading cause of death among women 25-44.
- 100,000 women are thought to be HIV positive. 44,403 women have been diagnosed with AIDS. In nine East Coast cities, AIDS is the leading cause of death among women aged 25-44.

California

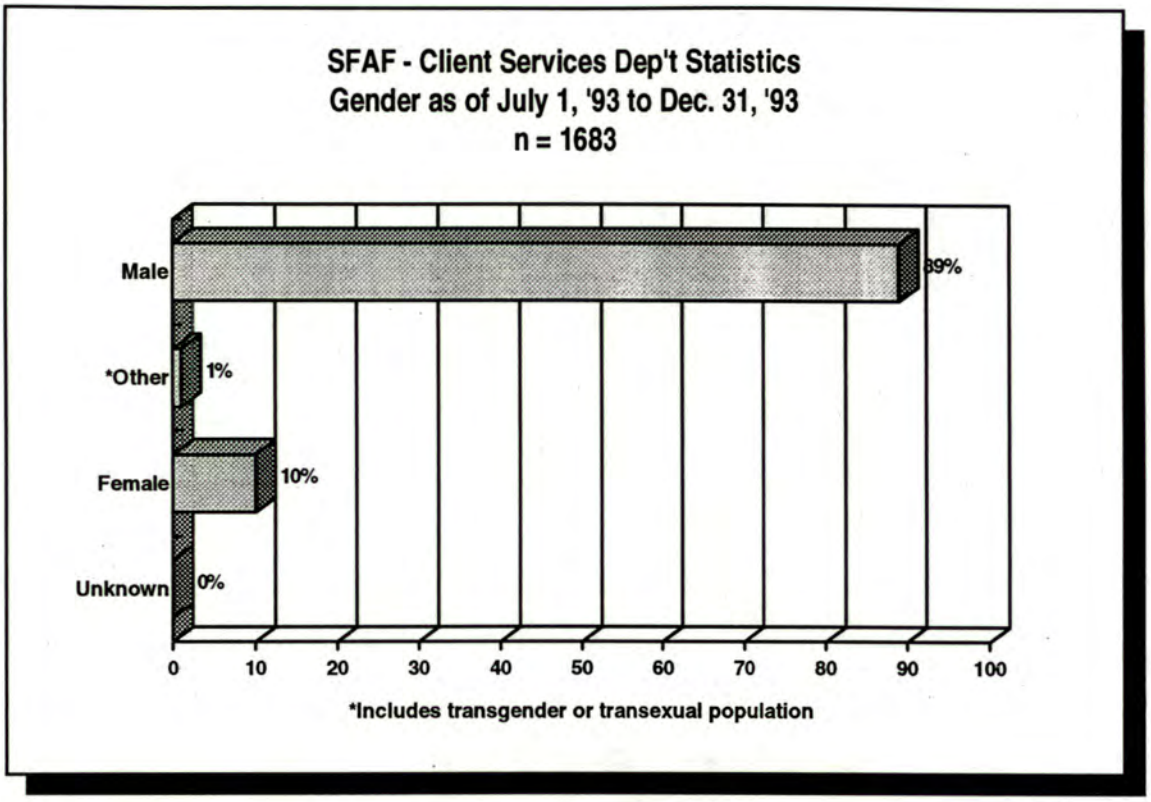
As of April 30, 1994...

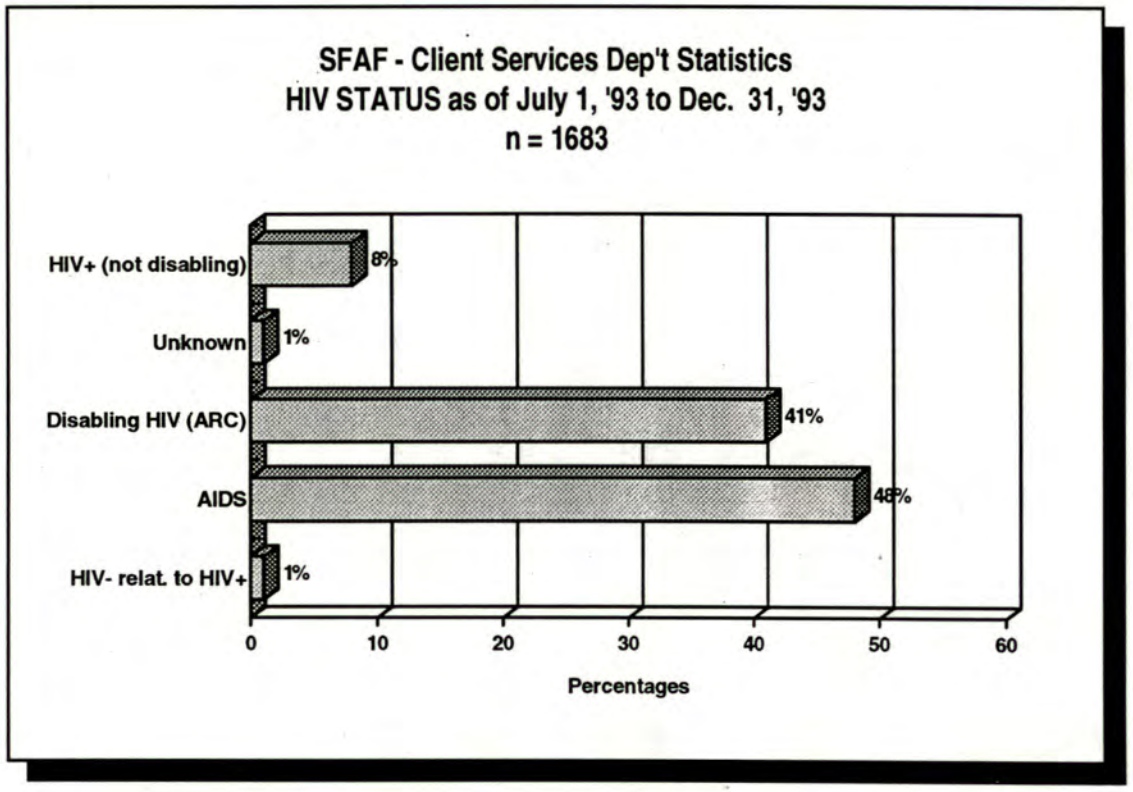
- 71,977 Californians have been diagnosed with AIDS. 44,388 Californians have died of AIDS.
- At least 150,000 Californians are thought to be HIV positive.
- AIDS has been the leading cause of death among men aged 25-44 in California for each of the past three years, and has surpassed cancer and motor vehicle accidents as the leading cause of potential years of life lost among all Californians.

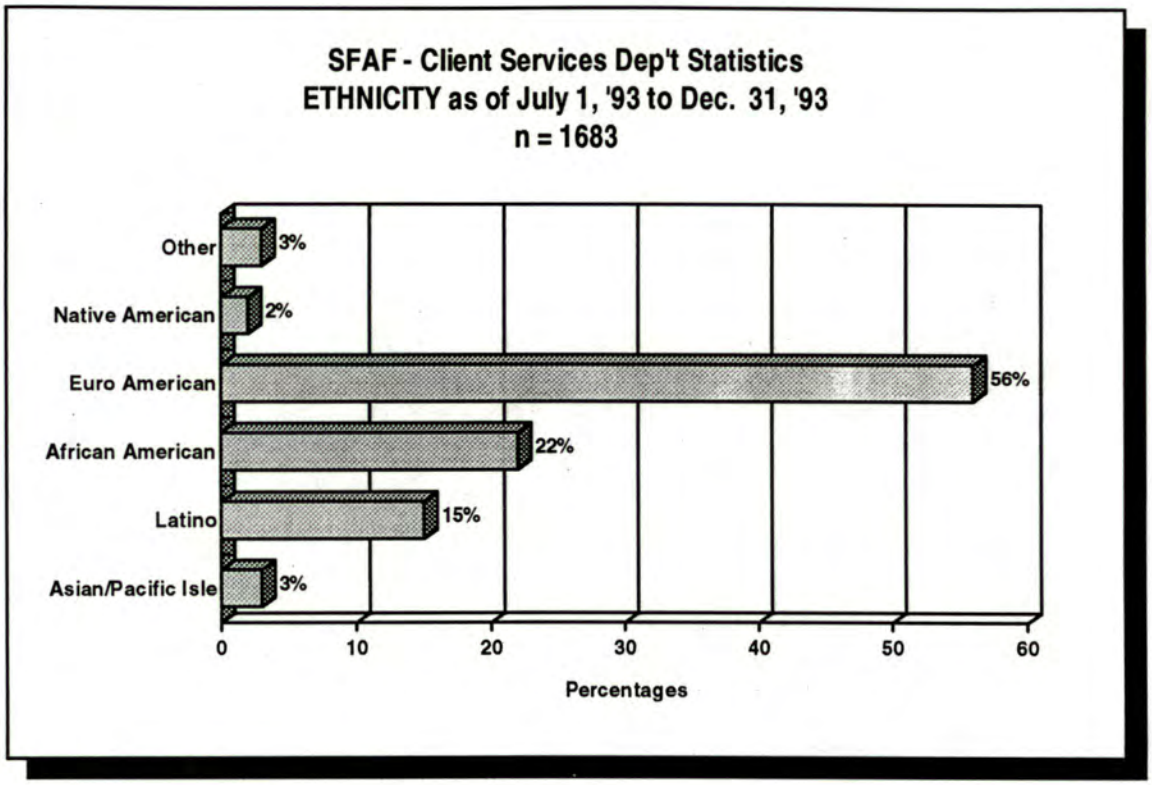
San Francisco

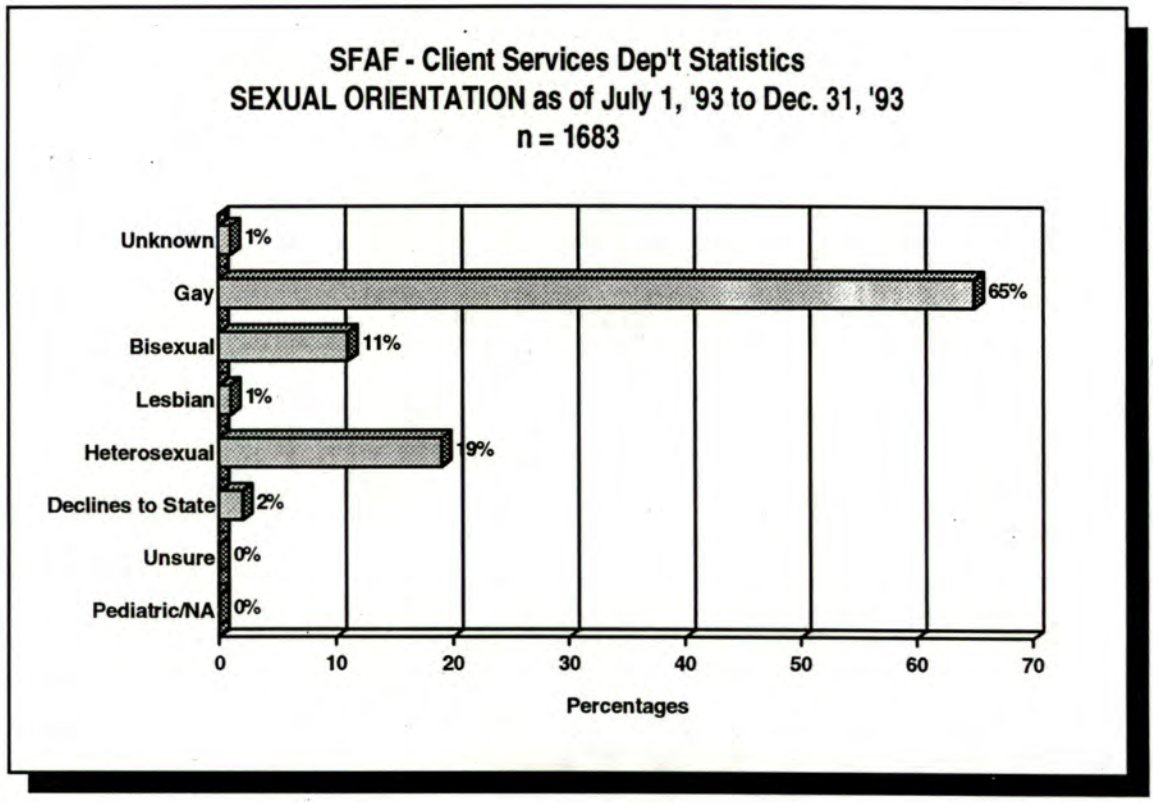
As of April 30, 1994...

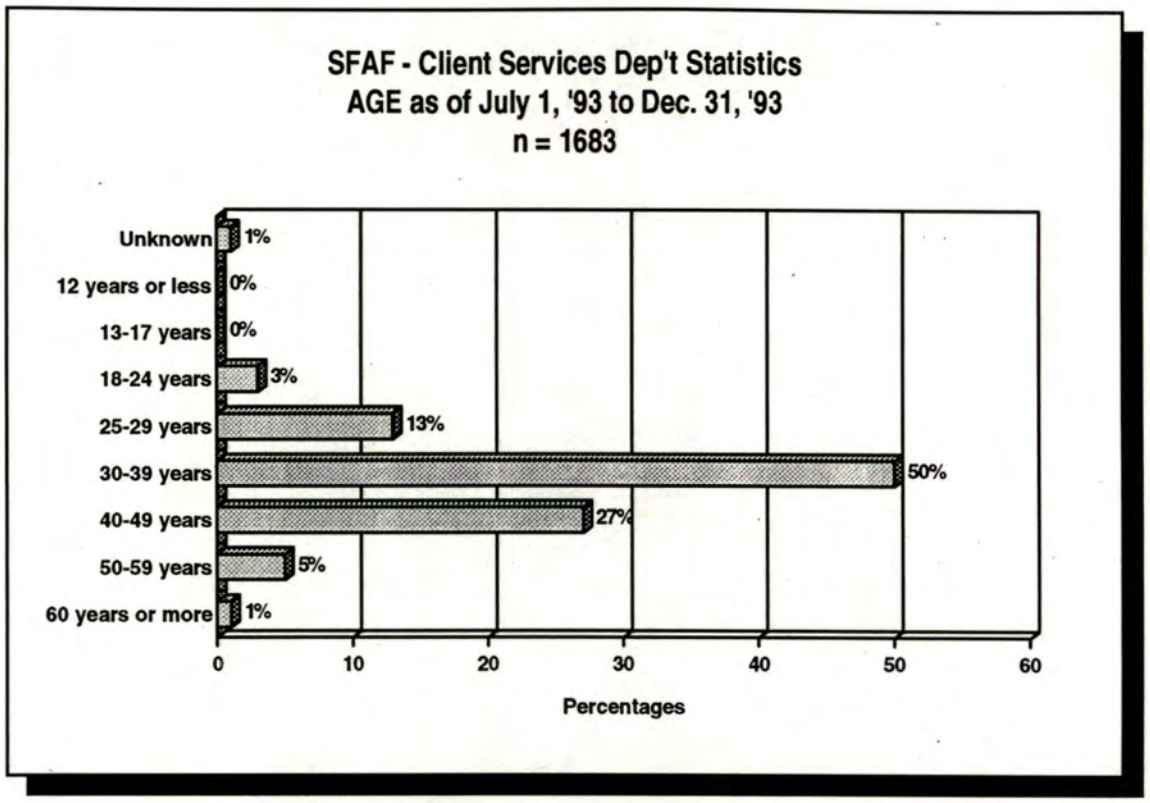
- The city of San Francisco ranks third in the nation in diagnosed cases of AIDS, surpassed only by New York and Los Angeles. San Francisco has the highest rate per capita of AIDS cases and HIV positive persons of any major U.S. city.
- 19,410 San Franciscans have been diagnosed with AIDS, of which 12,352 have died.
- 28,000 San Franciscans are thought to be living with HIV.
- In 1991, 61% of all deaths among men aged 25-44 in San Francisco were due to AIDS, the highest percentage in the U.S.
- In 1992, AIDS surpassed heart disease as the leading cause of death among men in San Francisco.

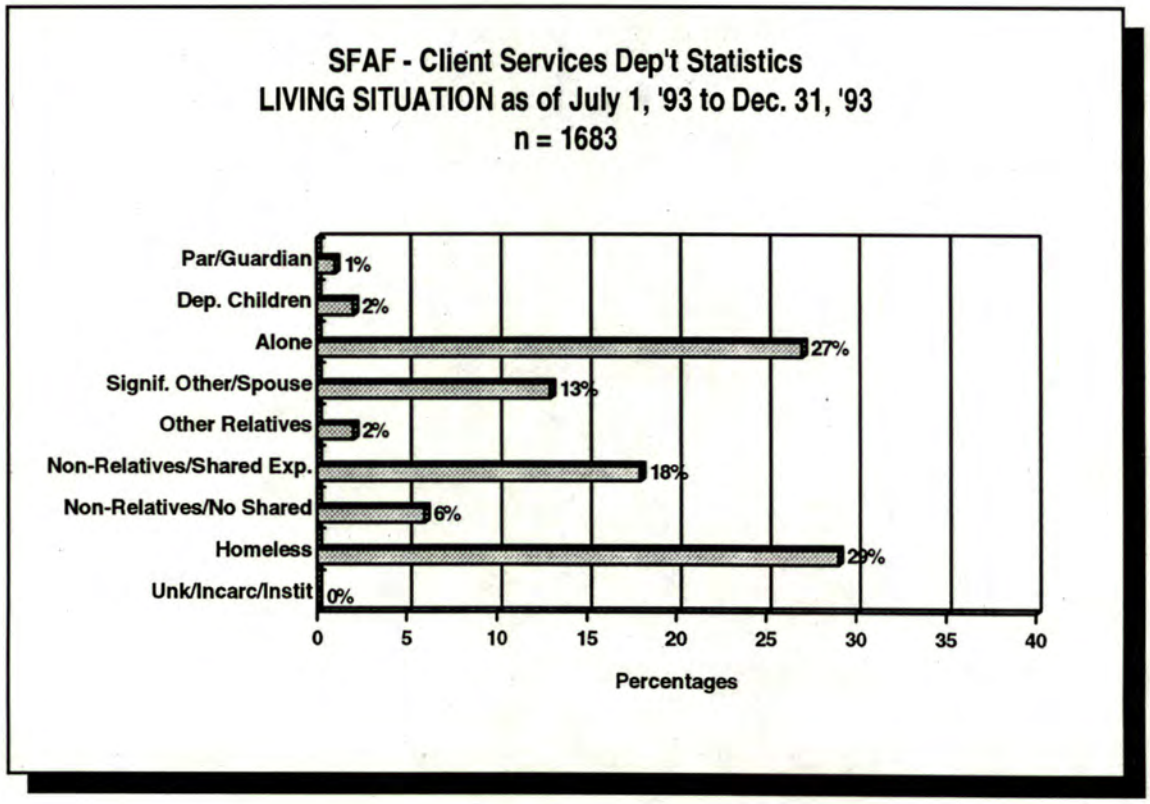

SFAF - Client Services Dep't Statistics
Gender as of July 1, '93 to Dec. 31, '93
n = 1683
Male
89%
*Other
1%
Female
10%
Unknown
0%
0
10
20
30
40
50
60
70
80
90
100
*Includes transgender or transexual population


SFAF - Client Services Dep't Statistics
HIV STATUS as of July 1, '93 to Dec. 31, '93
n = 1683
HIV+ (not disabling)
8%
Unknown
1%
Disabling HIV (ARC)
41%
AIDS
48%
HIV- relat. to HIV+
1%
0
10
20
30
40
50
60
Percentages

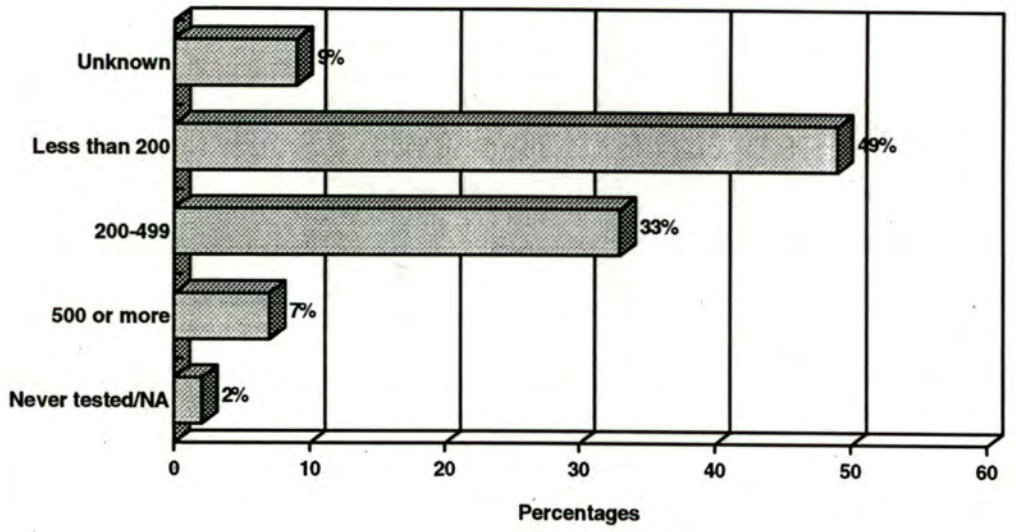

SFAF - Client Services Dep't Statistics
ETHNICITY as of July 1, '93 to Dec. 31, '93
n = 1683
Other
3%
Native American
2%
Euro American
56%
African American
22%
Latino
15%
Asian/Pacific Isle
3%
0
10
20
30
40
50
60
Percentages


SFAF - Client Services Dep't Statistics
SEXUAL ORIENTATION as of July 1, '93 to Dec. 31, '93
n = 1683
Unknown
1%
Gay
65%
Bisexual
11%
Lesbian
1%
Heterosexual
9%
Declines to State
2%
Unsure
0%
Pediatric/NA
0%
0
10
20
30
40
50
60
70
Percentages

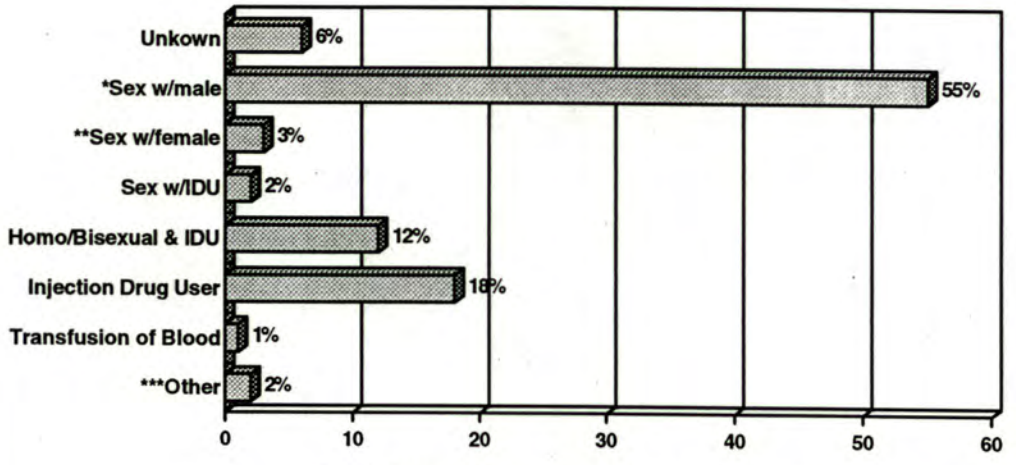

SFAF - Client Services Dep't Statistics
AGE as of July 1, '93 to Dec. 31, '93
n = 1683
Unknown
12 years or less
13-17 years
18-24 years
25-29 years
30-39 years
40-49 years
50-59 years
60 years or more
1%
0%
0%
3%
13%
50%
27%
5%
1%
0
10
20
30
40
50
60
Percentages


SFAF - Client Services Dep't Statistics
LIVING SITUATION as of July 1, '93 to Dec. 31, '93
n = 1683
Par/Guardian
Dep. Children
Alone
Signif. Other/Spouse
Other Relatives
Non-Relatives/Shared Exp.
Non-Relatives/No Shared
Homeless
Unk/Incarc/Instit
1%
2%
27%
13%
2%
18%
6%
29%
0%
0
5
10
15
20
25
30
35
40
Percentages

SFAF - Client Services Dep't Statistics
T-CELL COUNT as of July 1, '93 to Dec. 31, '93
n = 1683

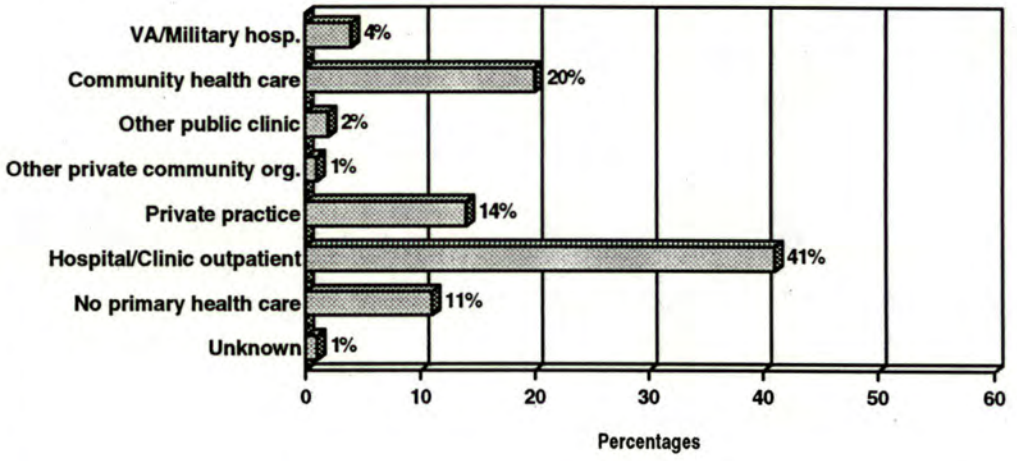


SFAF - Client Services Dep't Statistics
HIV EXPOSURE as of July 1, '93 to Dec. 31, '93
n = 1683

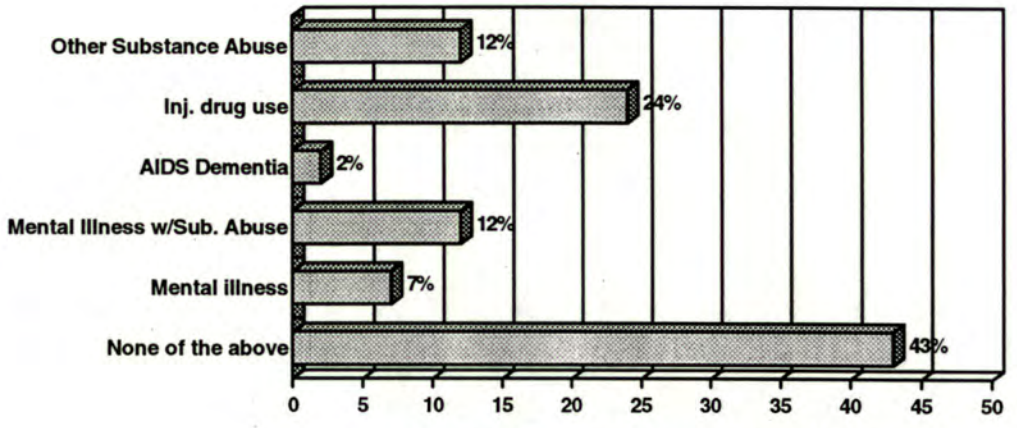


*includes heterosexual sex (women with men) **heterosexual contact only
***includes sexual abuse or assault, occupational exposure, and age less than 13 from mother

SFAF - Client Services Dep't Statistics
PRIMARY HEALTH CARE as of July 1, '93 to Dec. 31, '93
n = 1683

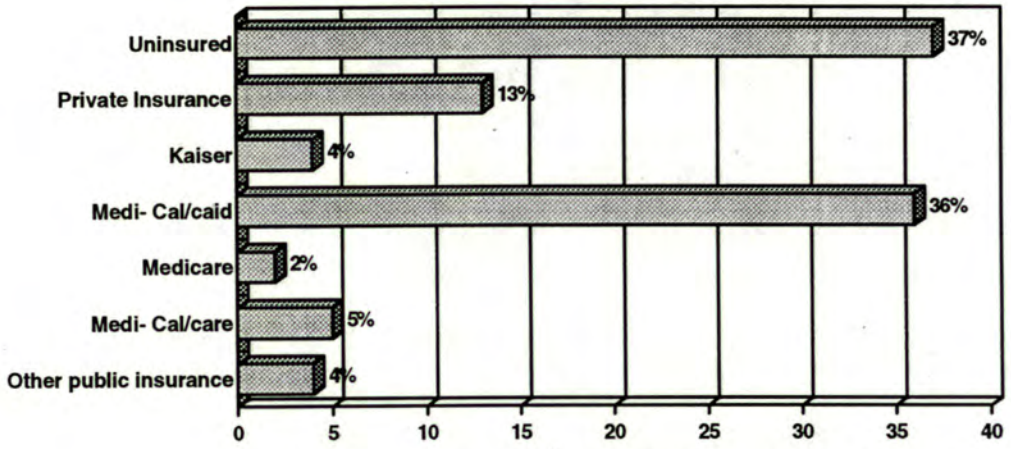


SFAF - Client Services Dep't Statistics
*SPECIAL POPULATION as of July 1, '93 to Dec. 31, '93
n = 1683



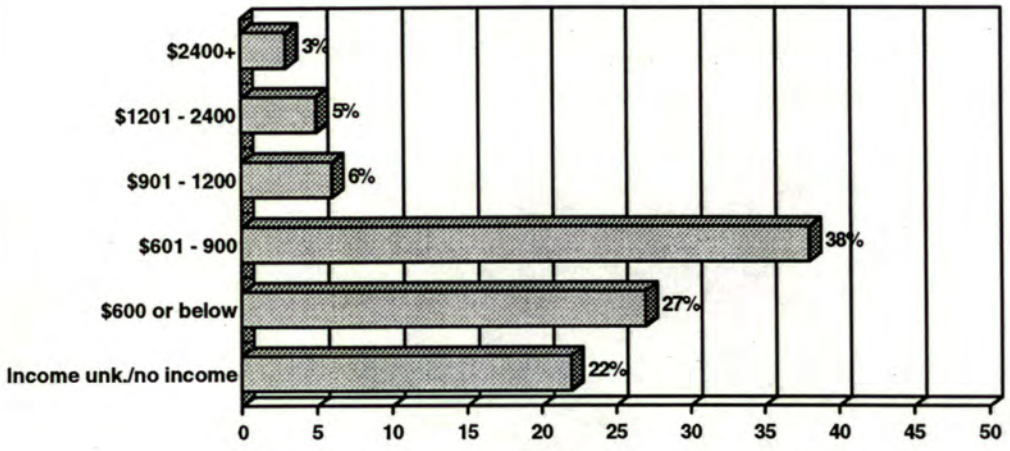
*Reflects secondary problematic area in clients life in addition to HIV infection

SFAF - Client Services Dep't Statistics
MEDICAL INSURANCE as of July 1, '93 to Dec. 31, '93
n = 1683



*Reflects clients that have been homeless one time or another due to their diagnosis

SFAF - Client Services Dep't Statistics
INCOME as of July 1, '93 to Dec. 31, '93
n = 1683

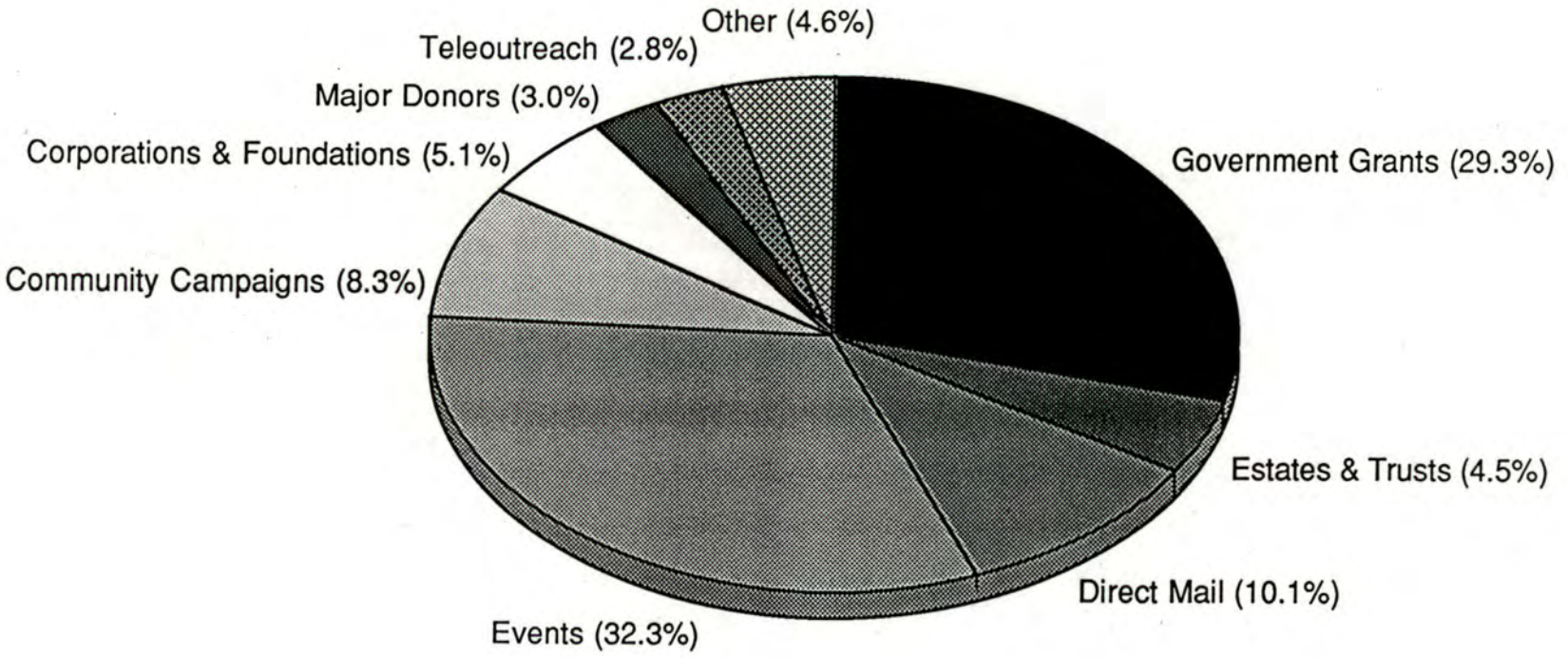


*Reflects clients that have been homeless one time or another due to their diagnosis

San Francisco AIDS Foundation

Income Analysis: FY 1992–1993

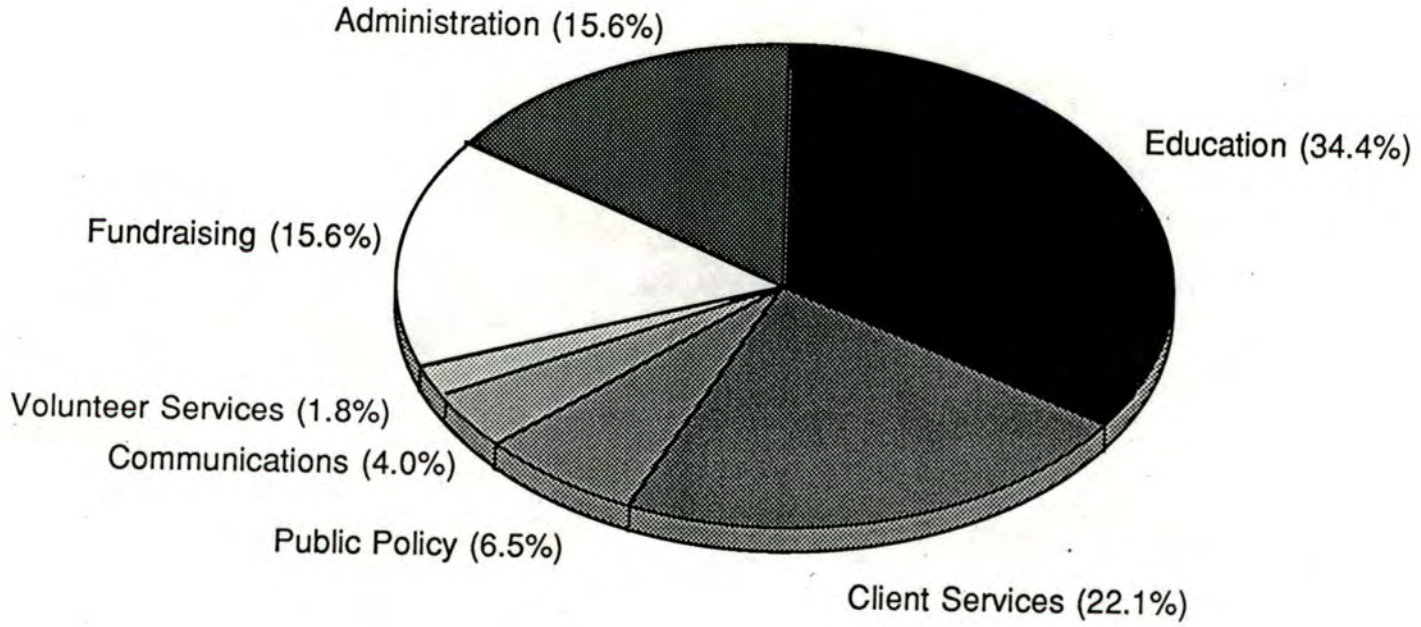
PRIVATE FUNDING: 70.7% GOVERNMENT FUNDING: 29.3%



Total Income: $7,214,545*

** This figure does not include donated services valued at $532,086*

San Francisco AIDS Foundation
Expense Analysis: FY 1992–1993



Total Expenses: $6,953,043

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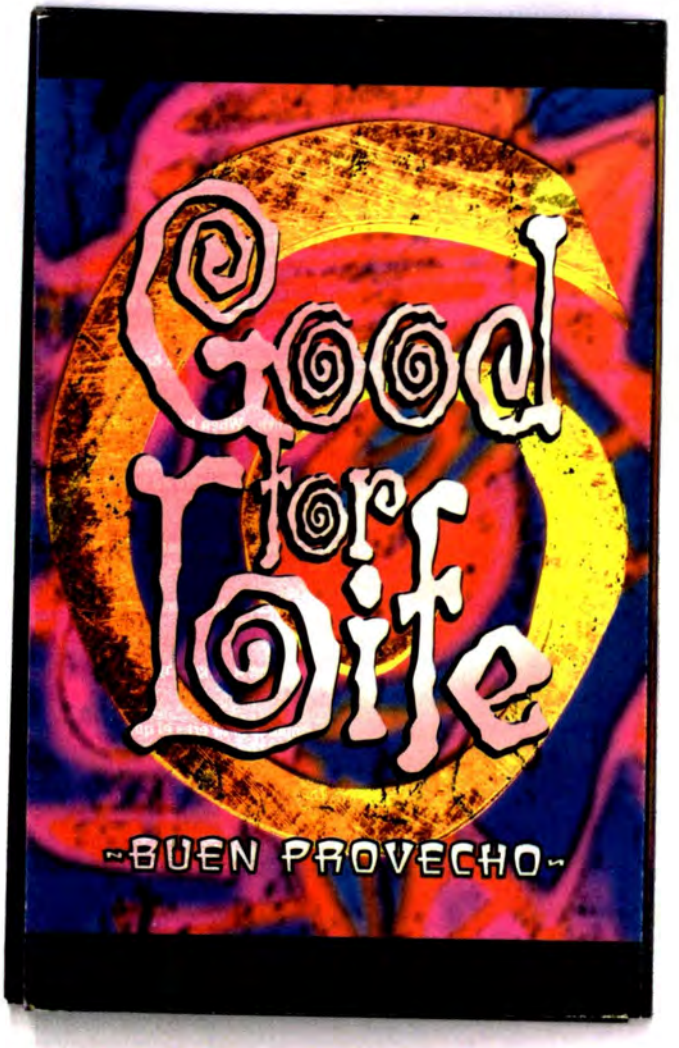
Good for Life

2pgs


Good for Life
~BUEN PROVECHO~

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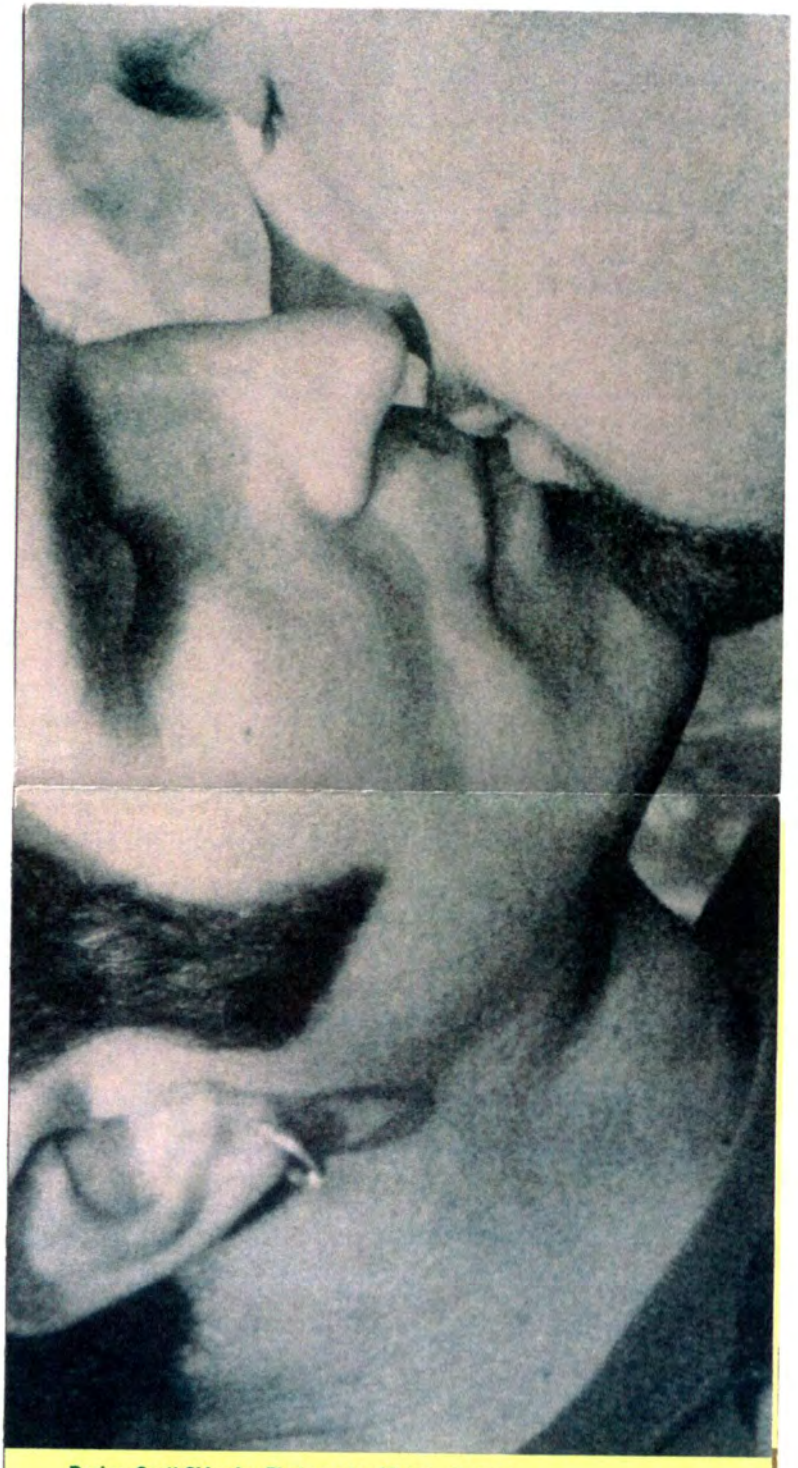
Right To Life

2pgs



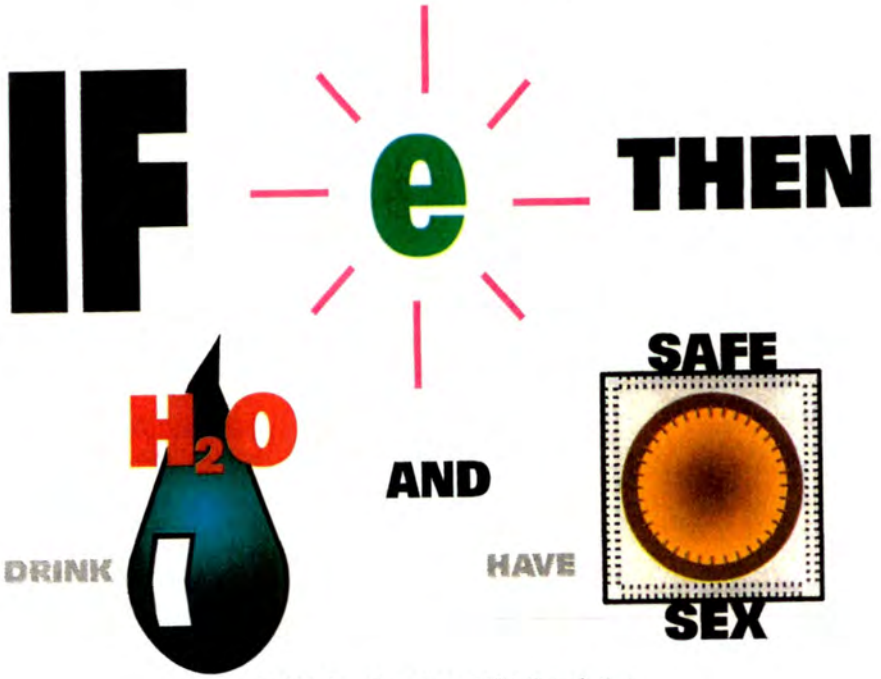
Design: Scott Sidorsky Photography: Michele Clement

LOVE YOUR BODY

For recorded info on ecstasy and safe sex call
415.985.7477

S.F. AIDS Foundation, Haight-Ashbury Free Clinics Inc.,

This flyer is in no way meant to encouraae the use of ecstasy



Out liv- ing

forecasts of doom

a postcard series for gay/bisexual men
from the sf aids foundation

Gotta Believe

Single Gay Man outliving the forecasts of doom. HERE WE ARE still pushing ahead. Positive or negative, we thought safe sex was just about surviving. There's more...

1993. Funded by: SF Dept. of Public Health and by foundation, corporate and individual donations. Photography: Stan Muselik. Design: Scott Sidorsky

Keep it safe.
Make a plan.
See it through.

SF AIDS FOUNDATION

Hotline 1-800-FOR-AIDS
English, Spanish, Filipino

Got places to go

Single Gay Man with plans to make. A few years ago, I couldn't think ahead to the next week. Now, I'm organizing the first Queer Space Shuttle Voyage. "10... 9... 8... 7! More than one way to get to heaven!"

1993. Funded by: SF Dept. of Public Health and by foundation, corporate and individual donations. Photography: Stan Muselik. Design: Scott Sidorsky

Keep it safe.
Make a plan.
See it through.

SF AIDS FOUNDATION

Hotline 1-800-FOR-AIDS
English, Spanish, Filipino

Got a story to tell

Single Gay Man. Mature enough to wonder—what would it mean to grow old gracefully? (I'll either be the studliest silverback male or the most menacing old queen on the planet.) In any case, WE WILL HAVE STORIES TO TELL.

1993. Funded by: SF Dept. of Public Health and by foundation, corporate and individual donations. Photography: Stan Muselik. Design: Scott Sidorsky

Keep it safe.
Make a plan.
See it through.

SF AIDS FOUNDATION

Hotline 1-800-FOR-AIDS
English, Spanish, Filipino

Gotta have a fantasy

Question: What has 2 legs in the morning, 4 legs at dinnertime, 6 legs—and hot, safe sex—at night?
Answer: Your tried and true relationship w/my fresh face on it. Single Gay Man seeks secure adventuresome couple.

1993. Funded by: SF Dept. of Public Health and by foundation, corporate and individual donations. Photography: Stan Muselik. Design: Scott Sidorsky

Keep it safe.
Make a plan.
See it through.

SF AIDS FOUNDATION

Hotline 1-800-FOR-AIDS
English, Spanish, Filipino

Gonna have to serve somebody

Single Gay Man, trained as a chef, architect and contractor. (Forgive me, but sometimes while licking your boots I feel... overqualified.) Sure, I can unroll a condom in complete darkness. I can also design your house, build it and serve you your first home-cooked meal. Why not use all of me?

1993. Funded by: SF Dept. of Public Health and by foundation, corporate and individual donations. Photography: Stan Musilik. Design: Scott Sidorsky

Keep it safe.
Make a plan.
See it through.

SF AIDS FOUNDATION

Hotline 1-800-FOR-AIDS

English, Spanish, Filipino

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What About Ecstasy

A practical Guide to MDMA

3pgs

be deadly if you get behind the wheel or do some other activity which you are actually too drunk to perform. Bad judgments may be made about sex, condoms, and protecting yourself.

Remember, while pure x is not addictive, some of the things that it is mixed with are. Also, if you use any downers or tranquilizers to take the edge off crashing, those pills can be very addictive and can lead to other problems. Many people report that a small amount of pot works best.

Want Help?

For more info on safe sex and on using different forms of protection, or on any other matter regarding HIV/AIDS, call the San Francisco AIDS Foundation Hotline, Monday to Friday 9am - 9pm, Saturday and Sunday from 11am - 5pm. Operators will take your calls in English, Spanish, or Filipino. The number to call is 1-800-FOR-AIDS.

If you think you are having a problem with ecstasy, acid, speed, alcohol, or any other drug, here are some numbers to call :

Haight - Ashbury Free Clinic
(415) 773-9898

18th Street Services (for gay/bi men)
(415) 861-4898

Drugline (24 hours)
(415) 752-3400

What about ecstasy

A Practical Guide to MDMA

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SF AIDS FOUNDATION

ADVANCE

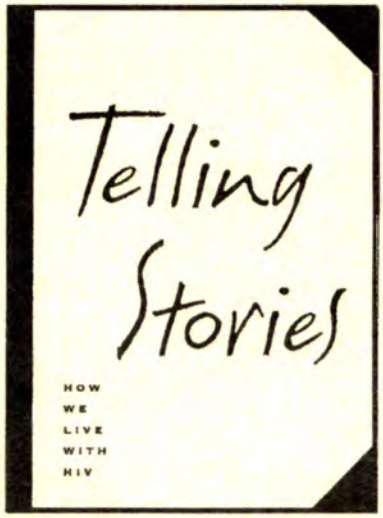
The monthly bulletin of the San Francisco AIDS Foundation • May, 1994 • Vol. 5, No. 4

The act or process of moving or going forward.

Telling Stories – SFAF's Leadership Dinner

by Bill Hayes & Clay Ellis Jones

The San Francisco AIDS Foundation's annual Leadership Recognition Dinner allows us to gather together to honor those who have had a significant impact in hastening the end of the HIV epidemic. At this year's dinner, the evening of Tuesday, May 10th, the Foundation will honor an outstanding individual, William D. Glenn, and a remarkable corporation, GAP/Banana Republic, for their contributions to the fight against AIDS. Bill Glenn, past president of our Board of Directors and key community leader over the past ten years, will receive the James R. Harrison Award. The Leadership Award will be presented to The GAP/ Banana Republic for its long-standing support of the Foundation, the AIDS Walk, and other community events.



Each year, the Leadership Dinner is a noteworthy, sold-out event attended by over 1,000 guests representative of community-based AIDS service providers, as well as individuals from corporate, governmental, and medical communities. In addition to recognizing those who have demonstrated their outstanding commitment to the fight against AIDS, the Leadership Dinner helps raise funds to support the Foundation's direct client service, education, and advocacy programs. Dinner co-chairs Karen Wegmann, Executive Vice-President of Wells Fargo Bank, and Reverend Cecil Williams of Glide

See Page 2

Grassroots Advocacy Hits the Capitols

by Ryan Clary

Photo By Beverly Tharp

Rex Palmer, Ryan Clary, and Steve Garber sending out Lobby Day flyers.

People living with HIV/AIDS, service providers, and other activists will converge on the state and U.S. capitols in May to lobby for increased funding for HIV programs and for comprehensive health care reform.

On May 16th, hundreds of advocates will participate in AIDS Budget Lobby Day at the State Capitol in Sacramento. This event is sponsored by the AIDS Budget Coalition, a statewide group of organizations representing HIV service providers and other advocates. Coalition members include AIDS Project Los Angeles, California Association of AIDS Agencies, LIFE AIDS Lobby, Planned Parenthood Affiliates of California, and the San Francisco AIDS Foundation.

See Page 2

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IMPETUS

WINTER 1994 • PUBLISHED BY THE SAN FRANCISCO AIDS FOUNDATION

Four-County Women's Education Project Launched

by Joe Fera

The San Francisco AIDS Foundation has joined forces with AIDS Project of Contra Costa, The Center (Alameda County), and the Aris Project (Santa Clara County) to establish a four-county HIV education and prevention project specifically designed for women. It is the first cooperative effort of its kind.

Recent statistics show that AIDS cases are increasing at a much faster rate among women as compared to men. AIDS cases among women now account for over 11% of total cases nationally. Among women aged 25-44, AIDS now ranks as the leading cause of death in nine East Coast cities and is the fourth most common cause of death nationwide.

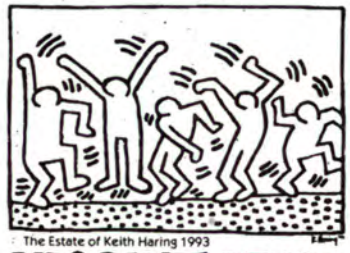
Other new national statistics show that fully 50% of new AIDS cases occurring among women are the result of sexual transmission. Traditionally, the majority of cases among women has been the direct result of injection drug use.

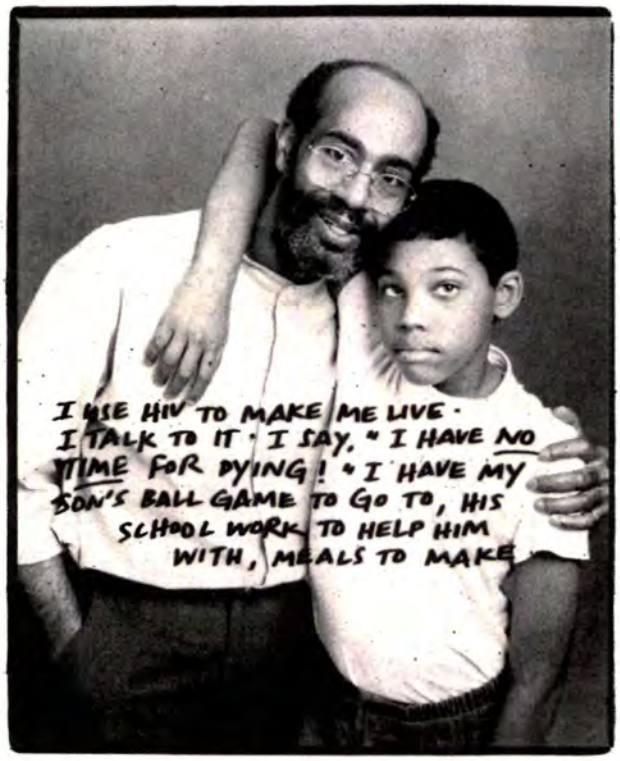
These statistics point to the need for comprehensive prevention education for women — not only those with a history of injection drug use, but also women who face potential risk as sexual partners of those who might be HIV infected.

The four-county project is funded through sales of radio station KKSF's *Sampler 3 for AIDS Relief.* KKSF's compact disc and cassette sampler project is an ongoing fundraising effort on behalf of the San Francisco AIDS Foundation and other local AIDS organizations.

While each of the four agencies involved in the new project already provides programs and services for women, this effort will serve to strengthen and enhance those efforts substantially.

"The San Francisco AIDS Foundation is proud and excited to be part of this groundbreaking four-county collaboration," said AIDS Foundation executive director Pat Christen. "It has always been a goal of the Foundation to increase education and prevention efforts for women. We are grateful to KKSF for their commitment to helping us achieve that goal." ◆





Annie Leibovitz

Early Care Campaign Goes National

by David S. Boyer

A local art gallery. The windows of a national chain of skin and hair care boutiques. *Road and Track* magazine. The bus shelters of San Francisco. All have played host to a recent San Francisco AIDS Foundation campaign which paired visually-striking portraits donated by photographer Annie Leibovitz with the empowering, impassioned, hopeful words of her HIV-positive subjects.

The campaign, which first appeared in May 1993 on bus shelters throughout San Francisco, features a diverse group of thirteen people living with HIV. The ads simultaneously challenge the stereotypes enshrouding the HIV/AIDS community and encourage a dialogue about getting tested and pursuing early treatment for the illness.

Ordinarily, a well-received, local effort which brings together America's foremost portrait photographer and local HIV-positive people would be considered an unqualified success. Period. But what is truly noteworthy is how,

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SF AIDS FOUNDATION

HIV Policy Watch

A MONTHLY PUBLIC POLICY UPDATE FROM THE SAN FRANCISCO AIDS FOUNDATION

May, 1994

STATE BUDGET AUGMENTATION GAINS SUPPORT AS LOBBY DAY NEARS

Three members of the Assembly have signed on to the AIDS Budget Coalition's augmentation request of $5 million to the state HIV/AIDS budget. The augmentation proposal calls for $3 M in additional funding for prevention and education programs, and another $2 M for counseling and testing.

Assemblyman Richard Katz (D-LA) has agreed to carry the augmentation proposal. Speaker Willie Brown (D-SF) and Assemblyman John Burton (D-SF) have both offered their support for the request as well. The AIDS Budget Coalition continues to arrange district meetings with key budget subcommittee members to advocate for increased funding.

With support for the augmentation increasing, it is more crucial than ever for a huge turnout for AIDS Budget Lobby Day on May 16th at the State Capitol in Sacramento. After a briefing on the state budget, participants will rally on the Capitol steps, where an array of speakers (including Speaker Brown) will address the crowd. Following the rally, everyone will meet directly with their elected representatives and/or legislative aides to demand increased funding and an end to cuts in entitlement programs.

The deadline for Lobby Day registration has been extended to May 9th! If you haven't already registered, call (415) 864-5855, x2537. Encourage your co-workers, clients, volunteers, etc. to participate in this important event. Limited bus transportation will be provided from San Francisco, Oakland, and Richmond.

GOOD AND BAD NEWS ON TESTING BILLS

Recent committee hearings in the Assembly and Senate produced a flurry of activity related to HIV testing this past month.

On the positive side, AB 3207 (Knight) and SB 1432 (Rogers) were defeated in the Assembly and Senate Health Committees. These dangerous bills would have redefined venereal disease to include HIV/AIDS and thus opened the door to mandatory testing, names reporting, and quarantining. Thanks to the work of LIFE AIDS Lobby, AIDS Project Los Angeles, ACT-UP, and a groundswell of grassroots opposition, these bills are dead for the time being.

However, mandatory testing for criminals appears popular this year, as AB 2815 (Boland), which requires mandatory testing for persons convicted of certain sex crimes, and AB 190X (Martinez), which allows victims of a serial rapist to petition the court for involuntary testing of the defendant, both passed the Assembly Public Safety Committee recently. Both bills are headed for Assembly Ways and Means and then the full Assembly.

SB 1239 (Russell), which would allow non-consensual testing of a patient's blood for HIV if a doctor or healthcare worker has experienced a "significant exposure", will be heard in the next few months by the Assembly Health Committee. This bill contradicts Department of Health Services' guidelines on preventing HIV transmission in a healthcare setting.

Now is the time to call your legislators to oppose all mandatory testing bills! Forced testing of criminals

and patients gives a false sense of security, is a waste of limited resources, and paves the way for mandatory testing of all Californians! For more information about these bills, call Robert Ríos, LIFE AIDS Lobby, at (916) 444-0424, or Pat Dunn at (415) 864-5855, x3039.

HIV PREVENTION REFORM UPDATE

State Community Prevention Planning:

On April 7th and 8th, the first meeting of the California Prevention Community Planning Working Group (CPWG) was held in Oakland. The Working Group is responsible for assisting the State Office of AIDS in developing a statewide prevention plan. This plan must be completed prior to the State's submission to the Centers for Disease Control and Prevention (CDC) of its request for FY 95 funding on October 3rd. While not required to do so by the CDC, the State Office of AIDS has committed to using the plan to prioritize the use of both federal and state HIV prevention funds.

At the Oakland meeting, working group members were briefed on their roles and responsibilities, apprised of the timeline under which their work is to be completed, and asked to make an ongoing commitment to participate in this collaborative process.

It was also announced that the sites for the June 7th/8th and Aug. 31st/Sept. 1st meetings of the CPWG had been changed. The revised schedule is as follows:

May 5th and 6th (Long Beach)
June 7th and 8th (Fresno)
July 14th and 15th (San Diego)
August 31st and September 1st (Redding)

Each meeting will include an opportunity for public comment. In addition, public hearings focusing on the draft plan will be held throughout the state during August. Contact the State Office of AIDS at (916) 323-7356 for specific locations.

In order for the HIV prevention needs of your community to be met it is crucial that you participate in this community planning process. Members of the statewide Community Planning Working Group (CPWG) need your input. Contact members from your area or community and offer them your ideas and expertise (see attached membership list). In support of this effort, varied activities are occurring around the Bay Area. To date:

• BAHAN is organizing community meetings and monitoring planning activities throughout the Bay Area. In April, meetings were held in Solano and Napa.

• Service providers in Santa Cruz, Monterey, and San Benito counties have organized to meet regularly throughout the planning process to coordinate their input to the working group.

• San Mateo County has decided to expand its existing HIV services planning body to formally address prevention issues as well, per the criteria set forth in the CDC guidance.

• In Alameda, a community forum will be held on May 11th to address prevention planning and other issues related to HIV.

Federal Prevention Reform:

The National HIV Prevention Working Group met in Washington, D.C. on April 26th and 27th to discuss implementation of the CDC's community planning process, and to meet with congressional appropriators regarding FY 95 funding.

Despite activists' initial praise for the CDC's efforts, working group members were dismayed to learn in February that the CDC's implementation of community planning nationwide has a number of critical problems that could undermind its success if not resolved in the near future. Specific concerns include:

• inadequate review by the CDC of states' and cities' plans, which will serve as the basis for FY 95 funding;

• limited evaluation of this new community planning process, despite the fact that it represents a funda-

mental shift in the way that prevention funds are to be allocated;

• lack of a broad, community-based process for review of grantees' applications; and

• lack of a long-term plan for technical assistance to support the community planning process and maximize local community involvement.

Based on discussions at the working group's April meeting, as well as meetings with key policymakers at the CDC and the Deparment of Health and Human Services (HHS), the working group is hopeful that these issues will be resolved in the near future so that the community planning process can reach its full potential.

If you would like to receive ongoing information about the implementation of the HIV prevention community planning process and federal prevention reform efforts, please join the Greater Bay Area HIV Prevention Working Group by calling Tomiko Conner at (415) 864-5855, x3091. The next meeting is Tuesday, May 10th from 11:00 am to 2:00 pm at 25 Van Ness, 5th floor training room in San Francisco. Please RSVP by calling (415) 864-5855, x2246.

NATIONAL HIV ACTION AGENDA

At an April 12th White House meeting, National AIDS Policy Coordinator Kristine Gebbie released a draft of the "National HIV Action Agenda", which consists of fifteen goals divided into four general categories including prevention, research, services, and so-called cross-cutting issues (see attached). According to Gebbie, this document represents a first attempt on the part of her office to develop a national agenda that reaches beyond the federal government to ask what the private sector and individuals can do to fight AIDS. The concern on the part of many meeting participants is that by trying to serve so many purposes, the document and its goal statements will be so broad as to be meaningless.

San Franciso representatives at the meeting raised a number of concerns, including the lack of specificity in some of the goals. For example, rather than advocate explicitly for federal support of needle exchange, the document refers to the need for "an array of HIV preventive services" for substance abusers. San Francisco representatives also suggested to Gebbie that a new section be added to the document to address discrimination issues, including the ban on HIV positive travelers, immigrants, and refugees. Another concern is the document's total lack of financial or other resource goals. Without specific costs attached to each goal, its usefulness is quite limited.

Community members have been asked to submit written comments via fax or mail. Gebbie is interested in hearing whether you think these goals are appropriate, if there are additional goals you would add, and what action steps you would propose be listed under each (see Goal O for example).

According to Gebbie, the final document will not be finalized until the new National AIDS Advisory Committee is convened. Gebbie stated that she was hopeful that the appointments to this committee would be made public within sixty days. The Advisory Committee will report directly to the President, with Gebbie serving as its Chairperson.

SOCIAL SECURITY CHANGES THREATEN RECENT GAINS

In 1993, after a two-year struggle, advocates and litigators for people with HIV and AIDS won a major victory by convincing the Social Security Administration (SSA) to update and expand the definition of disabling HIV disease for purposes of awarding Social Security disability benefits. Unfortunately, this victory may prove to be short-lived.

Recently, SSA announced a proposal to revamp the entire process by which it makes disability determiniations. SSA characterizes the proposal, released March 31st, as streamlining and enhancing the quickness of the SSA response to claims. These are important goals, as the SSA disability determination process takes too long and is too inefficient for all claimants, especially those with severe chronic

conditions or life-threatening diseases. Unfortunately, the SSA proposal also seems to "simplify" the definition of what equals a disability. The proposed standards could prove as problematic or more so for people with HIV/AIDS as the old HIV standards.

SSA is seeking comments from individuals and agencies by May 27th. For a copy of the proposal, call the SSA headquarters in Maryland at (410) 965-8882.

HEALTH CARE REFORM

The health care reform calendar is heating up dramatically in Congress. The schedule is important for our community to understand, so that we know when we will need to target specific letters, calls, and other actions to specific members of Congress to make sure we get reform that works for people with HIV/AIDS.

The latest plans call for the three major committees with jurisdiction over reform in the House of Representatives (Energy and Commerce, Education and Labor, and Ways and Means) to finish preparing their bills by Memorial Day. Then a dozen other House subcommittees or full committees will have two weeks (to mid-June) to address small portions of the proposals. The House leadership will no doubt end up with four competing bills that will have to be hammered into the final "democratic proposal" which needs 218 votes to pass the House in a floor vote expected by the August recess.

Last month, Representative Fortney (Pete) Stark (D-CA) jump-started the process with his Ways and Means subcommittee's passage of a Stark version of health care reform (see last issue of *HIV Policy Watch*). The full Ways and Means committee is in deliberations now and may start its formal "mark up" process with Stark's bill. The full Energy and Commerce committee is also working on an outline of a compromise bill — an effort the committee chairperson, Congressman John Dingell (D-MI) is spearheading. Neither the Stark bill nor the outline of the Dingell effort appear as good for people with HIV/AIDS as the Clinton or Wellstone/McDermott bills, but neither full committee has passed its final bill. Of all committees, Education and Labor is most likely to pass a bill best suited to the needs of people with HIV/AIDS. This committee may approve both an improved Clinton bill and a single payer bill.

On the Senate side, the Labor and Human Resources and Finance Committees will most likely vote on bills by late June. As with the House, a compromise bill will likely be crafted among the competing proposals left after the committees do their work, and a Senate floor vote would take place by the August recess. Senator Wellstone may also get a vote on his single-payer bill as well.

SFAF in conjunction with other HIV/AIDS advocacy groups continues to meet with representatives from the key Congressional offices to push our basic health care reform principles, as well as our long list of amendments we would like to see added to the President's proposal. Many of these amendments are also applicable to the Stark bill and other vehicles for reform being developed in these communities.

Now is the time to express your opinion on this crucial issue! Call or write your members of Congress and write a letter to the editor of your local paper! Contact the Policy Department at SFAF for more information on how to do this if needed.

SFAF Public Policy Staff:

Regina Aragón, Deputy Director for Public Policy
Ryan Clary, BAHAN Assistant
Tomiko Conner, BAHAN Community Organizer
Patricia Dunn, BAHAN Director
Paul Di Donato, Public Policy Associate
Eduardo Hernández, Public Policy Assistant
Rex Palmer, Volunteer Public Policy Assistant
Tom Zickgraf, Assistant to the Policy Director

Please forward questions, comments and suggestions for *HIV Policy Watch* to Ryan Clary, editor, at (415) 864-5855, x3032.

For information and referrals about AIDS and other HIV-related concerns, call the Trilingual AIDS Hotline: 1-800-FOR-AIDS.

STATE HIV-RELATED LEGISLATION: THE GOOD, THE BAD, & THE UGLY

Following are some of the most significant bills pending in the California State Legislature, and their status as of April 25th. We encourage you to contact your legislators about these bills. We would like to thank Robert Rios of LIFE AIDS Lobby for providing the information for this list. + = GOOD; - = BAD/UGLY

PREVENTION AND EDUCATION

AB 2610 (Bronshvag) - in Assembly Ways and Means +
SB 1048 (Watson) - in Assembly Health +
Would allow local jurisdictions to create pilot programs for one-on-one clean needle exchange. These are nearly identical to AB 260 (W. Brown), which was vetoed by Governor Wilson last year.

AB 3102 (Martinez) - in Assembly Ways and Means +
Would designate the State Office of AIDS as the lead state agency for HIV and AIDS policies, as recommended by the UCSF Institute for Health Policy Studies' evaluation of the Office of AIDS. Currently, no state agency is leading and coordinating California's response to the HIV pandemic.

SB 1351 (Marks) - in Assembly Public Safety +
Specifies that requesting a person to wear a condom does not equal consent for sexual intercourse. Inspired by Texas case where a woman asked her rapist to wear a condom.

SB 1364 (Marks) - in Senate Judiciary +
Would authorize a physician to prescribe marijuana for medical purposes.

CARE AND TREATMENT: WOMEN'S HEALTH

AB 2200 (Speier) - in Senate Health +
Would create an Office of Women's Health within the Department of Health Services, which would be charged with coordinating and promoting women's health policies, e.g., AIDS.

AB 2849 (Escutia) - in Assembly Ways and Means +
Would create a pilot "one-stop," comprehensive health center for women with HIV in a county with at least 100 women with HIV.

AB 3572 (Martinez) - in Assembly Ways and Means +
Would require health insurers to pay for experimental procedures and treatment when it is provided within any clinical trial, as defined by the American Society of Clinical Oncology.

AB 3749 (Margolin) - in Assembly Ways and Means +
Would require all health insurance plans to cover treatment and surgery for cervical cancer and cervical dysplasia, and annual screening tests for cervical cancer and sexually transmitted diseases. Also would add annual screening tests for sexually transmitted diseases and treatment for cervical cancer or dysplasia as covered benefits under Medi-Cal.

CARE AND TREATMENT: COMMUNITIES OF COLOR

AB 3501 (Martinez) - in Assembly Ways and Means +
Would reorganize and prioritize the state's efforts to address HIV infection and care for communities of color.

-- OVER --

HIV TESTING: (see article in attached Policy Watch)

AB 2815 (Boland) - in Assembly Ways and Means -
AB 109X (Martinez) - in Assembly Ways and Means -
SB 1239 (Russell) - in Assembly Health -

SB 1864 (Leslie) - in Senate Judiciary -
Would amend existing law regarding involuntary HIV testing for certain persons by including court-mandated testing for people who bite, scratch, spit at or otherwise exchange body fluids with a school or community college district employee.

HEALTH CARE: PRIVATE INSURANCE AND MEDI-CAL

SB 1357 (Torres) - in Senate Appropriations +
Would prevent insurance companies from denying Medicare supplemental policies to persons under 65 because of pre-existing conditions, currently prohibited by law for Medicare recipients over 65, but not for persons who qualify for Medicare due to a disability, such as AIDS.

SB 1363 (Marks) - in Senate Insurance +
Would prohibit health insurers from amending a health policy to deny or limit coverage available to a policy holder after the individual discloses an illness covered under the policy.

SB 1816 (Torres) - in Senate Insurance +
Would provide for injunctive relief for terminally-ill patients in a benefits coverage dispute with their health insurance company.

OTHER IMPORTANT BILLS:

ABX 20 (Andal) - on Assembly Floor -
SB 1260 (Presley) - in Assembly Public Safety -
Would repeal the "Inmates' Bill of Rights," which specifically allows prisoners basic rights such as to have personal visits or make a will. If signed into law, the Department of Corrections would have the right to authorize mandatory HIV testing of all prisoners without their consent.

AB 2810 - (Katz) - in Assembly Ways and Means +
Domestic Partners Registration Bill, would provide basic benefits for domestic partners including several that would benefit persons with AIDS: 1) right to visit a partner in the hospital; preferential ranking to be named conservator for an incapacitated partner; and 3) inclusion of domestic partners on California's statutory short form will.

AB 3232 (Alpert) - in Assembly Ways and Means +
Would add tuberculosis treatment as an optional benefit under Medi-Cal (also included in Governor's proposed budget).

California's Prevention Community Planning Working (voting) Group (CPWG) members by BAHAN county

**indicates member represents two jurisdictions*

ALAMEDA
Denison, Rebecca
WORLD

Flunder, Yvette, Reverend
The ARK of Refuge

***Sharen Trammell**

CONTRA COSTA
Reardon, Juan, M.D.
Contra Costa County Health Services Department

MARIN
Porter, Venetia
SPECTRUM - center for Lesbian, Gay, & Bisexual Concerns

MONTEREY
***MarioHernández**(also San Benito)

NAPA
O'Malley, Charlie
Napa County HIV Consortium

SAN FRANCISCO
Chang, Rafael
GCHP-GAPA Commnty HIV Project

Debrow, Brian
AIDS Office, C&C of San Francisco

*** Yvette Flunder**

Spieldenner, Andy
Lavender Youth Recreation Information Center

***Trammell, Sharen**
Black Coalition on AIDS

Yaranon, Doug
Asian AIDS Project
Nat'l Task Force on AIDS Prevention

SAN MATEO
***Copello, A. Gene, Ph.D.**
Conf of CA Local AIDS Directors

SANTA CLARA
Campos, Alex
Santa Clara County Health Department

SANTA CRUZ
***Hernández, Mario**
Salud Para La Gente

SOLANO

SONOMA
Learned, Andrea
Face to Face

STATEWIDE
***Gene Copello**

Kahn, James G., M.D., M.P.H.
UC-San Francisco
Dept. of Epidemiology

Norman, Pat, Co-chair
Multicultural Liaison Board

Jackson, Richard, MD, MPH,
Chief, Div.of Comm. Disease Control
California Department of Health

Tavera, Hank
National: LLEGO

California's Prevention Community Planning Advisory (non-voting) Group (CPAG) members by BAHAN county

ALAMEDA
Brinkley, Barry
Alameda County Health Care

***Thomas Lee Eades**

Lewis, David, Dr.
University Wide AIDS Research Program

CONTRA COSTA
MARIN
MONTEREY
NAPA

SAN FRANCISCO
Coates, Tom, Ph.D., Director
Center for AIDS Prevention Studies

***Conner, Tomiko**
SFAF/BAHAN Cmnty Organizer

Cristosomo, Vince
Asian AIDS Project

***Eades, Thomas Lee**
American Indian AIDS Institute

Francis, Donald, M.D., D.Sc.
Genentech Corporation

Franks, Pat
UCSF - Institute for Hlth Pol Studies

Herring, Marshia
AIDS Office, C&C of San Francisco

Newmeyer, John, Ph.D.
Haight Ashbury Free Clinic

***Osborne, Kerrington,**
Nat'l Task Force for AIDS Prev.

SAN MATEO
Carpenter, Peter
Stanford University

SANTA CLARA
Lenker, Su-Lin
Santa Clara County Health Dept.

SANTA CRUZ
Ellerby, Pat
AIDS Program
Santa Cruz Co. Hlth Srvcs Agency

Garcia, Barbara, Exec. Director
Salud Para La Gente

SOLANO
SONOMA

BAY AREA
***Tomiko Conner**
***Kerrington Osborne**

STATEWIDE
Sandoval, Chris, Project Director
Polaris Research & Development

Robert Ríos
Life AIDS Lobby

revised 4/20/94 TC

(Original signature of Member)

103D CONGRESS
2D SESSION

H.R. 4370

IN THE HOUSE OF REPRESENTATIVES

Mr. NADLER introduced the following bill; which was referred to the Committee on _____

A BILL

To establish the AIDS Cure Project.

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 "AIDS Cure Act".

SEC. 2. ESTABLISHMENT OF PROJECT TO CURE AIDS.

(a) IN GENERAL.—The President shall in accordance with this Act direct the Secretary of Health and Human Services to establish a project for the purpose of developing a cure for acquired immune deficiency syndrome (in this Act referred to as "AIDS"). The program may not be administered by any officer or employee of the National Institutes of Health. Subject to the preceding sentence, the Governing Council shall designate an individual to serve as a liaison between the Governing Council of the project (established under section 4(a)), the Secretary, and the President.

(b) DEFINITION.—For purposes of this Act, the term "cure", with respect to AIDS, means any and all approaches which will ensure a well-functioning immune system and a normal life span with a reasonable quality of life.

(c) CERTAIN REQUIREMENTS.—The Governing Council, in carrying out the project under subsection (a), shall ensure that the following requirements are met:

(1) The project shall pursue comprehensive basic science investigations, based on diverse theories and schools of thought which elucidate the pathogenesis of AIDS.

(2) The project shall identify, based on this work, all promising curatives and oversee their timely and adequate testing through the extraordinary powers detailed in section 5.

SEC. 3. OPEN AND PRODUCTIVE RESEARCH PATHS.

The Governing Council, in carrying out the project under section 2, shall ensure that the following requirements are met:

(1)(A) Thorough consideration shall be given to both conventional and other medical approaches and scientific theories, and researchers representing divergent approaches shall be on the primary research staff as well as be contributing researchers.

(B) The project shall aggressively pursue research into all areas of AIDS pathogenesis, including but not limited to—

(i) virological/immunological theories about how immune system damage occurs, including understudied approaches; and

(ii) theories about co-factors which may precede, activate or even substitute for HIV in the process of immune system damage leading to AIDS.

(C) Examination shall be given to the full spectrum of pathogenesis theories, from those maintain-

ing that HIV is the sole and sufficient cause to those considering HIV a primary cause together with co-factors to those believing that HIV does not necessarily play a causative role.

(D) Further work shall be done on the potential role of recreational drugs and environmental toxins in progression. The role of nutrition, exercise, and adequate primary health care must also be researched in the project. Psychoneuroimmunology and the connections between psychological stress and immune compromise shall also be studied.

(E) A diversity of theories should be developed and tested through both laboratory experiments and epidemiological research, including careful examination of cases of people with HIV and AIDS and interviews with people with HIV and AIDS and their care providers including but not limited to primary care clinicians, gynecologists, nutritionists, alternative or holistic practitioners, and mental health workers.

(F) All research funded in this Act shall be conducted in conformity with the ethics and privacy of current medical research.

(G) Researchers shall study epidemiological and blood studies of long-term survivors from diverse

populations to attempt to isolate the factors that have sustained them.

(H) Consideration shall be given to the hypotheses and results obtained in other countries. Researchers from other countries shall be invited to participate in the project. This may include agreements with another country to reassign particular researchers to the project for an indefinite commitment. The project's progress shall not await the conclusion of such international agreements.

(2) The project's study of AIDS pathogenesis and manifestations must focus on all populations of people with AIDS and HIV. Equal consideration shall be given to the differences between these populations as to their similarities or norms. This includes, but is not limited to people of all age groups (including children and seniors), gender, sexual orientation, women (regardless of reproductive health status), gay men, lesbians, people of color (of various affected national-cultural groups), injection drug users, prison inmates, people with hemophilia and people with inadequate medical care or nutrition (or both), and persons with disabilities and chronic conditions related to AIDS.

(3) Basic science investigations and therapeutic results shall be geared to people at every point on the spectrum of AIDS and HIV—from the sickest to the healthiest. Saving people considered near death must be considered as important as early intervention.

(4) Information generated by the project shall be made freely available worldwide to researchers, health care providers, people with AIDS and HIV and their advocates as soon as it is available, without being inhibited by professional publication practices. Funds shall be available as needed for the dissemination and translation of project materials.

(5) Curatives and therapies ultimately released due primarily to project research shall not result in financial gain to any private organization, and shall be made available to all affected people worldwide regardless of ability to pay. The project shall be responsible for establishing a mechanism for international funding and distribution of any such curatives.

SEC. 4. EFFICIENT AND COOPERATIVE MANAGEMENT OF PROJECT.

(a) GOVERNING COUNCIL.—

(1) IN GENERAL.—The project under section 2 shall be governed by, not merely advised by, a council composed of scientists and clinicians representing divergent approaches, and people with AIDS and HIV, and their advocates, from all affected communities. This council shall set policy and oversee research priorities, ethical standards, conflict of interest rules and hiring of researchers, and administrators.

(2) CERTAIN AUTHORITIES.—The Secretary shall ensure that the following requirements are met with respect to the council under paragraph (1):

(A) The council shall be composed of scientists representing divergent approaches, clinicians with both research and community-based experience and people with AIDS and HIV and their advocates.

(B) The council shall have at least 21 members in order to adequately represent diverse communities, opinions and disciplines. People with AIDS and HIV from diverse communities shall be in the majority to ensure that the project staff are ultimately accountable to people directly affected by the course and outcome of the research. Council members shall

step down and be replaced by new members on a regular basis.

(C) The Council shall set policy for and oversee research priorities. It shall develop guidelines for and oversee the hiring of primary research staff, ensuring both high quality (scientific credentials and experience) and a diversity of disciplines and perspectives (including alternative" or holistic approaches). Having pursued specific AIDS theories shall not be a necessary prerequisite for hiring. The Council shall have the power to create new research positions when necessary and to remove scientists from their positions after due process and appropriate review of their work.

(D) The Council shall be charged with evaluating the work of the project, as well as the pace of the research, to ensure that it matches the urgency of the epidemic. Initially, and throughout the life of the project, the Council, in cooperation with the primary research staff, shall solicit and evaluate theories developed outside the project. It shall direct the project scientists to evaluate and respond to de-

serving proposals and to devise new research plans where desirable.

(E) The Council shall adopt strict, detailed codes governing medical ethics and conflicts of interest and shall monitor compliance with these codes. Project scientists shall report directly to the council about the progress of their work in a manner to be determined by the council. The Council shall report to the President through the liaison about the progress of the project.

(F) Council meetings, including those at which all decisions are made, shall be public and shall be held at least quarterly, with time allotted for public comment. In addition, the Council shall hold an annual public hearing on its priorities and progress. A complete report of the project's goals and accomplishments shall be updated by the Council, submitted to the President and released to the public at least once quarterly. The Council shall evaluate its structure and process at least once per year and make changes which allow it to function more effectively.

(G) Members of the Governing Council will not be paid employees of the project. However, the Governing Council will be provided with an operating budget, including but not limited to, the following purposes: Support staff; creation and dissemination of reports and other materials; funds for transportation and other per diem expenses; and funds for convening public meetings.

(b) REQUIREMENTS.—The Governing Council, in carrying out the project under section 2, shall ensure that the following requirements are met:

(1) The project shall establish a primary location for its work, in an area with a high incidence of AIDS. All primary research staff shall work at that location; contributing researchers located around the world shall interact via video teleconferencing, an international computer network, and regularly scheduled face-to-face meetings.

(2) The National Institutes of Health's existing AIDS research programs shall be maintained. All National Institutes of Health basic science research supplementary to that done by the project shall be performed cooperatively with the project in coordination with the Office of AIDS Research.

(3)(A) All primary research staff and administrators shall be financially compensated only by the project and may not have conflicts of interests with private or public organizations (including but not limited to universities, pharmaceutical companies, and private research organizations).

(B) All primary research staff and administrators shall be required to suspend their relationship with any private or public organizations for the duration of their association with the project. These requirements shall include full-time, part-time, or consultant positions with a private or public organization or other government agencies, and the suspension would include employment, consulting or board membership fees, and stock or business ownership.

(C) The Governing Council members shall be required to suspend their relationship with for-profit organizations which represent a conflict of interest.

(4) The project shall be funded by public, not private monies. Appropriations for the project shall not be diverted from other health research, health care, or human service programs.

(5) The project shall, in addition to basic research investigations, operate an on-site clinic to conduct small scale research trials with human par-

ticipants if such trials are crucial for testing hypotheses related to its basic research.

(c) COORDINATING COMMITTEE.—The Governing Council shall ensure that a coordinating committee is established for the project under section 2, in accordance with the following:

(1) The community of scientists selected for the project shall elect three of their members to serve as the coordinating committee for the project, and determine whether these positions should be permanent or rotating.

(2) The coordinating committee shall be responsible for facilitating communication among the different scientists working on the project, for evaluating the progress of its work, and for convening the entire staff on a regular schedule (or when necessary) to evaluate the progress of the project as a whole, identify gaps in research, reevaluate the project's direction, and to consider newly developed theories emanating from both within and outside the project.

(3) The coordinating committee shall also be responsible for keeping the Governing Council informed of the progress of the project's work, at times and in a manner to be determined by the Gov-

erning Council. The coordinating committee shall also make decisions regarding the hiring of research associates, technical staff, purchases of equipment and other day-to-day needs.

(4) The first task of the coordinating committee shall be to facilitate a preliminary review of all existing pathogenesis hypotheses, as well as other relevant information about AIDS pathogenesis. At the end of this review, which shall last no longer than 3 months, the primary research staff shall collectively develop plans for evaluating and testing each of the viable hypotheses, including timelines for evaluating the progress of this work, and submit these plans to the Governing Council for review and comments.

(d) SELECTION OF GOVERNING COUNCIL.—

(1) IN GENERAL.—The Secretary of Health and Human Services (HHS) shall convene a national AIDS congress to make recommendations to the President for selecting the Governing Council. The AIDS congress will meet only once, and for the sole purpose of nominating the initial Governing Council. The Secretary of HHS shall solicit nominations from a wide variety of sources, including, but not limited to, each of the following: AIDS activist groups;

health care providers; AIDS advocacy organizations; AIDS service organizations; community-based AIDS research organization; biomedical researchers and nonmainstream (including alternative or holistic) medical organizations; and health care planning agencies, who shall send their nominations for the Governing Council to the AIDS congress. The AIDS congress will make recommendations to the President for the Governing Council. The President shall select the Governing Council based on the recommendations of the AIDS congress. The AIDS congress will consist of 2 representatives chosen by each of the HIV health services planning councils under section 2602(b) of the Public Health Service Act, chosen in a forum that is open to the public by each of the HIV planning councils. The President shall widely publicize the request for nominations.

(2) DATE CERTAIN FOR SELECTION.—In keeping with the emergency nature of this project, the nomination and selection process must be completed within 3 months of the enactment of this Act.

SEC. 5. EXTRAORDINARY POWERS.

In carrying out the project under section 2, the Governing Council shall have extraordinary powers to carry out the following:

(1)(A) Utilize, in cooperation with the agencies, any and all existing United States Government funded research entities nationwide (including but not limited to the AIDS Clinical Trial Group (ACTG), the Community Program for Clinical Research on AIDS (CPCRA)), and their facilities to clinically test promising cures developed on the basis of its research and to direct the manner in which such research shall proceed, including staffing, participants, location, and timing. Such research shall be funded by the project.

(B) The project shall design its own protocols and work with these existing clinical trial programs to develop research designs and methods appropriate to the project's goals, assuring that data gathered by the NIH would accurately reflect the use of these compounds in all populations and stages of illness.

(C) The project shall provide funding for these clinical trials of its own compounds. In areas of conflict, the project shall have the power to implement its goals.

(2) Exercise the right of eminent domain to carry out the following:

(A)(i) Obtain from public and private organizations, with just compensation, samples of

all potential curatives and all data (excluding medical records) regarding their development (including safety and efficacy data) as well as other information, materials, or products deemed crucial to the project, but protect the privacy of research subjects and the researcher over which the project will be exercising the right of eminent domain. The project shall use its power of eminent domain only after reasonable attempts at cooperation have failed.

(ii) To use eminent domain power, the project must determine and identify whether this research is essential information to the project's research and that it is unavailable other than through eminent domain.

(iii) Once obtaining through eminent domain the research of an outside researcher, the project shall make all efforts to preserve appropriate recognition of the scientist's work. The project shall also afford any researcher, whose work is acquired through eminent domain, an opportunity to participate in the project with just compensation.

(B) If a drug company is found to be impeding or halting the development of a promis-

ing compound, the project shall first attempt to work with the company to develop the needed timetable for research and trials. A company lacking the resources to develop a compound shall have the option of selling the patent to the project for just compensation, or allowing portions of its development to be undertaken by the project.

(C) If, however, a company refuses to cooperate with the project by not releasing needed data, or by withholding samples of requested compounds, whether under development or not, the project is authorized to use powers of eminent domain to procure samples and data. The project shall have the power to obtain the patents of such compounds if, after reasonable attempts at cooperation, it finds that a company will not develop a promising compound according to an approved timeframe by the coordinating committee. After notification by the project that this power will be used, a company shall have 30 days in which to develop, for the project's approval, a plan for accelerated development of the compound to avoid losing exclusive rights to the patent. Unless said companies

adhere to an approved timeframe and are forthcoming with their data as such work proceeds, then the project can implement clinical testing for potential curatives by private companies.

(D) Use existing pharmaceutical company facilities (with just compensation) for the production of promising curatives to be utilized in project research and, if effective, to produce such curatives in sufficient amounts to be disseminated to all people needing them.

SEC. 6. PLANNING FUNDS.

Funds shall be allocated immediately to be used for planning of the project under section 2 (including creating facilities, selection of staff, funding, structure, and schedules), so that the project can begin functioning as soon as is possible.

SEC. 7. REAUTHORIZATION OF PROJECT.

After 5 years of operation, the Congress shall have the power to reauthorize the project under section 2.

103D CONGRESS
2D SESSION

H.R. 4370

IN THE HOUSE OF REPRESENTATIVES

Mr. NADLER introduced the following bill; which was referred to the Committee on _____

A BILL

To establish the AIDS Cure Project.

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 "AIDS Cure Act".

SEC. 2. ESTABLISHMENT OF PROJECT TO CURE AIDS.

(a) IN GENERAL.—The President shall in accordance with this Act direct the Secretary of Health and Human Services to establish a project for the purpose of developing a cure for acquired immune deficiency syndrome (in this Act referred to as "AIDS"). The program may not be administered by any officer or employee of the National Institutes of Health. Subject to the preceding sentence, the Governing Council shall designate an individual to serve as a liaison between the Governing Council of the project (established under section 4(a)), the Secretary, and the President.

(b) DEFINITION.—For purposes of this Act, the term "cure", with respect to AIDS, means any and all approaches which will ensure a well-functioning immune system and a normal life span with a reasonable quality of life.

(c) CERTAIN REQUIREMENTS.—The Governing Council, in carrying out the project under subsection (a), shall ensure that the following requirements are met:

(1) The project shall pursue comprehensive basic science investigations, based on diverse theories and schools of thought which elucidate the pathogenesis of AIDS.

(2) The project shall identify, based on this work, all promising curatives and oversee their timely and adequate testing through the extraordinary powers detailed in section 5.

SEC. 3. OPEN AND PRODUCTIVE RESEARCH PATHS.

The Governing Council, in carrying out the project under section 2, shall ensure that the following requirements are met:

(1)(A) Thorough consideration shall be given to both conventional and other medical approaches and scientific theories, and researchers representing divergent approaches shall be on the primary research staff as well as be contributing researchers.

(B) The project shall aggressively pursue research into all areas of AIDS pathogenesis, including but not limited to—

(i) virological/immunological theories about how immune system damage occurs, including understudied approaches; and

(ii) theories about co-factors which may precede, activate or even substitute for HIV in the process of immune system damage leading to AIDS.

(C) Examination shall be given to the full spectrum of pathogenesis theories, from those maintain-

ing that HIV is the sole and sufficient cause to those considering HIV a primary cause together with co-factors to those believing that HIV does not necessarily play a causative role.

(D) Further work shall be done on the potential role of recreational drugs and environmental toxins in progression. The role of nutrition, exercise, and adequate primary health care must also be researched in the project. Psychoneuroimmunology and the connections between psychological stress and immune compromise shall also be studied.

(E) A diversity of theories should be developed and tested through both laboratory experiments and epidemiological research, including careful examination of cases of people with HIV and AIDS and interviews with people with HIV and AIDS and their care providers including but not limited to primary care clinicians, gynecologists, nutritionists, alternative or holistic practitioners, and mental health workers.

(F) All research funded in this Act shall be conducted in conformity with the ethics and privacy of current medical research.

(G) Researchers shall study epidemiological and blood studies of long-term survivors from diverse

populations to attempt to isolate the factors that have sustained them.

(H) Consideration shall be given to the hypotheses and results obtained in other countries. Researchers from other countries shall be invited to participate in the project. This may include agreements with another country to reassign particular researchers to the project for an indefinite commitment. The project's progress shall not await the conclusion of such international agreements.

(2) The project's study of AIDS pathogenesis and manifestations must focus on all populations of people with AIDS and HIV. Equal consideration shall be given to the differences between these populations as to their similarities or norms. This includes, but is not limited to people of all age groups (including children and seniors), gender, sexual orientation, women (regardless of reproductive health status), gay men, lesbians, people of color (of various affected national-cultural groups), injection drug users, prison inmates, people with hemophilia and people with inadequate medical care or nutrition (or both), and persons with disabilities and chronic conditions related to AIDS.

(3) Basic science investigations and therapeutic results shall be geared to people at every point on the spectrum of AIDS and HIV—from the sickest to the healthiest. Saving people considered near death must be considered as important as early intervention.

(4) Information generated by the project shall be made freely available worldwide to researchers, health care providers, people with AIDS and HIV and their advocates as soon as it is available, without being inhibited by professional publication practices. Funds shall be available as needed for the dissemination and translation of project materials.

(5) Curatives and therapies ultimately released due primarily to project research shall not result in financial gain to any private organization, and shall be made available to all affected people worldwide regardless of ability to pay. The project shall be responsible for establishing a mechanism for international funding and distribution of any such curatives.

SEC. 4. EFFICIENT AND COOPERATIVE MANAGEMENT OF PROJECT.

(a) GOVERNING COUNCIL.—

(1) IN GENERAL.—The project under section 2 shall be governed by, not merely advised by, a council composed of scientists and clinicians representing divergent approaches, and people with AIDS and HIV, and their advocates, from all affected communities. This council shall set policy and oversee research priorities, ethical standards, conflict of interest rules and hiring of researchers, and administrators.

(2) CERTAIN AUTHORITIES.—The Secretary shall ensure that the following requirements are met with respect to the council under paragraph (1):

(A) The council shall be composed of scientists representing divergent approaches, clinicians with both research and community-based experience and people with AIDS and HIV and their advocates.

(B) The council shall have at least 21 members in order to adequately represent diverse communities, opinions and disciplines. People with AIDS and HIV from diverse communities shall be in the majority to ensure that the project staff are ultimately accountable to people directly affected by the course and outcome of the research. Council members shall

step down and be replaced by new members on a regular basis.

(C) The Council shall set policy for and oversee research priorities. It shall develop guidelines for and oversee the hiring of primary research staff, ensuring both high quality (scientific credentials and experience) and a diversity of disciplines and perspectives (including alternative" or holistic approaches). Having pursued specific AIDS theories shall not be a necessary prerequisite for hiring. The Council shall have the power to create new research positions when necessary and to remove scientists from their positions after due process and appropriate review of their work.

(D) The Council shall be charged with evaluating the work of the project, as well as the pace of the research, to ensure that it matches the urgency of the epidemic. Initially, and throughout the life of the project, the Council, in cooperation with the primary research staff, shall solicit and evaluate theories developed outside the project. It shall direct the project scientists to evaluate and respond to de-

serving proposals and to devise new research plans where desirable.

(E) The Council shall adopt strict, detailed codes governing medical ethics and conflicts of interest and shall monitor compliance with these codes. Project scientists shall report directly to the council about the progress of their work in a manner to be determined by the council. The Council shall report to the President through the liaison about the progress of the project.

(F) Council meetings, including those at which all decisions are made, shall be public and shall be held at least quarterly, with time allotted for public comment. In addition, the Council shall hold an annual public hearing on its priorities and progress. A complete report of the project's goals and accomplishments shall be updated by the Council, submitted to the President and released to the public at least once quarterly. The Council shall evaluate its structure and process at least once per year and make changes which allow it to function more effectively.

(G) Members of the Governing Council will not be paid employees of the project. However, the Governing Council will be provided with an operating budget, including but not limited to, the following purposes: Support staff; creation and dissemination of reports and other materials; funds for transportation and other per diem expenses; and funds for convening public meetings.

(b) REQUIREMENTS.—The Governing Council, in carrying out the project under section 2, shall ensure that the following requirements are met:

(1) The project shall establish a primary location for its work, in an area with a high incidence of AIDS. All primary research staff shall work at that location; contributing researchers located around the world shall interact via video teleconferencing, an international computer network, and regularly scheduled face-to-face meetings.

(2) The National Institutes of Health's existing AIDS research programs shall be maintained. All National Institutes of Health basic science research supplementary to that done by the project shall be performed cooperatively with the project in coordination with the Office of AIDS Research.

(3)(A) All primary research staff and administrators shall be financially compensated only by the project and may not have conflicts of interests with private or public organizations (including but not limited to universities, pharmaceutical companies, and private research organizations).

(B) All primary research staff and administrators shall be required to suspend their relationship with any private or public organizations for the duration of their association with the project. These requirements shall include full-time, part-time, or consultant positions with a private or public organization or other government agencies, and the suspension would include employment, consulting or board membership fees, and stock or business ownership.

(C) The Governing Council members shall be required to suspend their relationship with for-profit organizations which represent a conflict of interest.

(4) The project shall be funded by public, not private monies. Appropriations for the project shall not be diverted from other health research, health care, or human service programs.

(5) The project shall, in addition to basic research investigations, operate an on-site clinic to conduct small scale research trials with human par-

ticipants if such trials are crucial for testing hypotheses related to its basic research.

(c) COORDINATING COMMITTEE.—The Governing Council shall ensure that a coordinating committee is established for the project under section 2, in accordance with the following:

(1) The community of scientists selected for the project shall elect three of their members to serve as the coordinating committee for the project, and determine whether these positions should be permanent or rotating.

(2) The coordinating committee shall be responsible for facilitating communication among the different scientists working on the project, for evaluating the progress of its work, and for convening the entire staff on a regular schedule (or when necessary) to evaluate the progress of the project as a whole, identify gaps in research, reevaluate the project's direction, and to consider newly developed theories emanating from both within and outside the project.

(3) The coordinating committee shall also be responsible for keeping the Governing Council informed of the progress of the project's work, at times and in a manner to be determined by the Gov-

erning Council. The coordinating committee shall also make decisions regarding the hiring of research associates, technical staff, purchases of equipment and other day-to-day needs.

(4) The first task of the coordinating committee shall be to facilitate a preliminary review of all existing pathogenesis hypotheses, as well as other relevant information about AIDS pathogenesis. At the end of this review, which shall last no longer than 3 months, the primary research staff shall collectively develop plans for evaluating and testing each of the viable hypotheses, including timelines for evaluating the progress of this work, and submit these plans to the Governing Council for review and comments.

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(1) IN GENERAL.—The Secretary of Health and Human Services (HHS) shall convene a national AIDS congress to make recommendations to the President for selecting the Governing Council. The AIDS congress will meet only once, and for the sole purpose of nominating the initial Governing Council. The Secretary of HHS shall solicit nominations from a wide variety of sources, including, but not limited to, each of the following: AIDS activist groups;

health care providers; AIDS advocacy organizations; AIDS service organizations; community-based AIDS research organization; biomedical researchers and nonmainstream (including alternative or holistic) medical organizations; and health care planning agencies, who shall send their nominations for the Governing Council to the AIDS congress. The AIDS congress will make recommendations to the President for the Governing Council. The President shall select the Governing Council based on the recommendations of the AIDS congress. The AIDS congress will consist of 2 representatives chosen by each of the HIV health services planning councils under section 2602(b) of the Public Health Service Act, chosen in a forum that is open to the public by each of the HIV planning councils. The President shall widely publicize the request for nominations.

(2) DATE CERTAIN FOR SELECTION.—In keeping with the emergency nature of this project, the nomination and selection process must be completed within 3 months of the enactment of this Act.

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In carrying out the project under section 2, the Governing Council shall have extraordinary powers to carry out the following:

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(A)(i) Obtain from public and private organizations, with just compensation, samples of

all potential curatives and all data (excluding medical records) regarding their development (including safety and efficacy data) as well as other information, materials, or products deemed crucial to the project, but protect the privacy of research subjects and the researcher over which the project will be exercising the right of eminent domain. The project shall use its power of eminent domain only after reasonable attempts at cooperation have failed.

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(iii) Once obtaining through eminent domain the research of an outside researcher, the project shall make all efforts to preserve appropriate recognition of the scientist's work. The project shall also afford any researcher, whose work is acquired through eminent domain, an opportunity to participate in the project with just compensation.

(B) If a drug company is found to be impeding or halting the development of a promis-

ing compound, the project shall first attempt to work with the company to develop the needed timetable for research and trials. A company lacking the resources to develop a compound shall have the option of selling the patent to the project for just compensation, or allowing portions of its development to be undertaken by the project.

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adhere to an approved timeframe and are forthcoming with their data as such work proceeds, then the project can implement clinical testing for potential curatives by private companies.

(D) Use existing pharmaceutical company facilities (with just compensation) for the production of promising curatives to be utilized in project research and, if effective, to produce such curatives in sufficient amounts to be disseminated to all people needing them.

SEC. 6. PLANNING FUNDS.

Funds shall be allocated immediately to be used for planning of the project under section 2 (including creating facilities, selection of staff, funding, structure, and schedules), so that the project can begin functioning as soon as is possible.

SEC. 7. REAUTHORIZATION OF PROJECT.

After 5 years of operation, the Congress shall have the power to reauthorize the project under section 2.