

A NEW STRATEGY FOR ACTIVISM

Until now AIDS activism has targeted drug companies heavily and Congress lightly, if at all. Targeting drug companies has obvious advantages. They profit from AIDS; the more of us that suffer, the more they profit. Naturally, we tend to dislike, envy and mistrust them. It is easy to stir anger against drug "profiteers," easy to scapegoat them. Anger gives us power, scapegoating allows uses of power that conscience wouldn't otherwise sanction. For recruitment and building solidarity, the drug companies are clearly the target of choice.

However, even though companies like Burroughs Wellcome deserve our criticism, the strategy of targeting the drug industry has flaws so serious they necessitate a new strategy. What are these flaws?

While the cost of drugs is too high, high profits are only one of the causes. Drugs are expensive because of the costs of securing FDA approval, which has now risen to an awesome 231 million dollars average per drug. Reduce the costs of approval, and drugs will be developed faster and can be sold at lower prices. But the authority to reduce the costs of approval does not belong to the drug companies; it belongs to Congress which--through its brainchild the FDA--has encouraged unconscionably slow and absurdly cautious approval policies.

Albeit scapegoating drug companies fuels AIDS activism, scapegoating itself can blind us to the true nature of our problem and, thus, to its solution. Because we scapegoat drug companies, we fail to see that they are hamstrung to give us what we need most: faster development of and wider access to new treatments. We fail to recognize that the surest way to accelerate development and expand access is to correct the faulty policies that govern development and access.

The drug companies "greed" can turn them into cooperative allies in the fight for better approval policies. Both drug companies and patients (and not just AIDS patients) can profit from faster, less expensive drug approval. Drug companies have money; activists have compelling motivation. The drug companies can be persuaded to fund

studies of alternatives to the status quo and finance a campaign for change. Activists can bring moral pressure on Congress to encourage new policies for approving drugs for life threatening diseases.

The new policies must respect the individual's right to informed consent. They must value human life and individual choice above "flawless" scientific methodology. They must carefully watch cost-benefit ratios and limit liability to provide as much safety as the public wants to pay for, but no more. Finally, they must respond in a democratic manner to the wishes of affected patient groups. The recently released Lasagna Commission Recommendations are a big step in the right policy direction.

In fact, Lasagna might make reforming approval policies on drugs for life threatening diseases surprisingly easy. Current FDA policies lack determined backers like the gun or tobacco lobbies. Conservatives might favor Lasagna based reform as de-regulation. Liberals might embrace reform to lower drug costs. Large drug companies prefer the less regulated European systems. Humanitarians want to see treatments speeded to those in need. Congressional enthusiasm for protection at all costs is largely confined to a handful of self-proclaimed consumer watchdogs. Politicians who try to protect us to death could be aggressively targeted as the "Gang of Five" were targeted at the recent International AIDS Conference.

To speed treatment development and expand access, activists must forgo simplistic scapegoating and accept the challenge of policy reform. Adjusting our thinking will be difficult, but new strategies can spur changes that may save our lives.

James Driscoll, Ph. D.

**ACT UP/Golden Gate
General Meeting Agenda
11/26/91**

**ACT UP
GOLDEN GATE
HEALTH
CARE
IS A
RIGHT**

Welcome!

- a. Introduction of facilitators
- b. Call for media/law enforcement
- c. Statement of purpose
- d. Explanation of our decision making process
- e. Call for timekeeper and two vote counters
- f. Agenda review and additions
- g. Pass the bucket. Donations go towards paying for the meeting space
- h. Welcome newcomers
- i. Security reminder! Walk with a friend!!

1. General body introductions

2. Outreach/Newcomers

Adam

3. Secretary's report

Lynne/Nade

4. Treasurer's report

Adam

5. General announcements/Pass sign-up sheets

Outreach -Bill, Tabeing -Bill, Treatment Issues Meeting

6. Educationals

- a. Ryan White/CARE Funding

Mike S

30 min

7. Proposal

- a. Letter endorsement -ASTRA Pharmaceuticals
- b. Letter endorsement -Competitiveness Committee

G'Dali

10 min

Treatment

10 min

8. Report-backs

- a. D.S.S. meeting
- b. Agnos meeting

Kent

10 min

Patrick

10 min

9. Discussion

- a. National HIV Coming Out Day

Ed

5 min

10. Miscellaneous

- a. Red Hot and Blue Committee

Andrea

15 min

11. Committee Reports

10 min

12. Evaluations



Committees represented at last night's coordinating committee meeting were: General body/Treasurer, Treatment Issues, Fundraising/Outreach, Local Issues, Insurance and Women's action. Absent from coordinating was: secretary and one general body rep. Funds approved included \$40 to attend Life Lobby meeting and \$10 for Living with HIV book (A book which lists SF services for women and children with HIV)

ACT UP/Golden Gate's Statement of Purpose

ACT UP/Golden Gate is a diverse, non-partisan group of individuals, united in anger and committed to direct action to end the AIDS crisis. We are engaged in a battle to reform the research and treatment of HIV and its associated opportunistic diseases, intensify HIV education and prevention efforts, and revolutionize the healthcare delivery system in this country. The HIV pandemic crosses all racial, age, sexual, cultural and class boundaries and we are committed to involving all affected communities in this fight. The fight against the HIV pandemic is our highest priority.

ACT UP/Golden Gate's Decision Making Process

ACT UP/Golden Gate operates on a 2/3 majority vote process. Proposals are brought to the floor. After the proposal has been made, there is a call for clarifying questions and a time for discussion. When discussion has ended, the question is called and seconded. At this time a vote is taken. Facilitators will ask for nays, abstentions and ayes. In order for the proposal to pass it must receive 2/3 majority vote.

ACT-UP Network Conference Call-11/10/91
AUGG Rep: Marvin

1. Red, Hot & Blue Update.

Money is being wired directly from London sometime this week. Funds will be distributed as soon as possible.

2. Membership dues-AU Network.

AUGG needs to pay our annual dues to the network in the amount of \$100.00.

3. World AIDS Day 1991.

This year emphasis for WAD is "Needle Exchange/Substance Abuse"

Seattle - AUS is working with other groups to formulate a needle exchange program for Washington. They will be conducting a needle exchange on the steps of the state capitol in Olympia.

San Diego - AUSD is working for a needle exchange program for their city

Philadelphia - Will conduct a needle exchange on 12/1/91, and turn the needles over to the city health officials at a press conference.

4. People of Color Treatment Conference.

A conference, open exclusively to POC, will occur in St. Louis. Tentative dates are 6/3-6/7/92. The focus will be Treatment Issues within minority communities. More information will follow in the mail.

5. Republican National Convention.

The 1992 Republican National Convention is in Houston. AU has reserved 100 rooms for those wishing to attend. Chapters will be required (hotel rules) to prepay for one days room rental for each room needed. Cost will be \$39.00 per room, per day.

Network is also seeking national endorsements of this action from the chapters. More information will be distributed as soon as it is received.

Anyone interested in the RNC should call Jim, AUKC at 816.753.5930.

CITY HALL ISSUES COMMITTEE (CHIC)
COMMITTEE REPORT - 11.19.91

Prepared by Jerry Windley

CHIC will attempt to put out a committee report on a weekly basis. This is not a guarantee that it will happen, but we'll make a valiant effort.

Listed below are the issues we are currently working on:

DEPARTMENT OF SOCIAL SERVICES

We met with Cooley Windsor and Larry Barnes, members of the DSS AIDS Awareness Group and DSS employees, at our last meeting. Initially we discussed the issue of having condoms & safe sex information available at all DSS offices. Many of the clients that depend on DSS services are HIV+ and do not have the means to purchase condoms. Additionally, some DSS clients may be HIV+ but have chosen either not to self-identify, or have never been tested. Providing condoms to DSS clients will help prevent HIV+ people from re-infecting themselves and protect HIV- people from infection.

The AIDS Awareness Group (AAG) is comprised of DSS employees who provide AIDS-related information to DSS clients. Two years ago some members of the AAG made condoms available to their clients. The acting general manager at the time, Rose Lou Randolph, forced AAG to stop giving clients condoms. Her reason was very simple. Ms. Randolph found the practice to be "inappropriate."

Since then, Art Agnos appointed his former legislative aide, Julia Lopez, as DSS General Manager. Ms. Lopez has done everything she can to avoid this issue and has shied away from providing information/condoms to DSS clients. Ms. Lopez has used the time-worn excuse of "lack of funds" as her reason for not pursuing this issue.

We find this to be outrageous. Ms. Lopez reportedly makes over \$100,000 annually; DSS recently purchased five 1992 model cars for top DSS administrative staff after trading in their 1990 models; the Deputy General Manager, Claude Finn reportedly makes \$100,000 annually; and, Ms. Lopez's staff is extremely top heavy with unnecessary positions filled by relatives of city officials and old friends. It appears that Ms. Lopez's priorities are a bit skewed.

The cost of providing condoms to DSS clients is estimated to be \$60,000. If the DSS can afford these over-inflated salaries and purchase new cars every two years, it does not seem unreasonable that it could afford to provide life saving information and condoms to the people it is mandated to serve.

Our discussion with Cooley and Larry brought out several other problems with the DSS and the services it "provides." For example, the DSS does not maintain any statistics relating to number of HIV+ clients it serves. Realizing that many people do not wish to self-identify, DSS could not have a complete accounting, but to have no records at all is preposterous. How can DSS know if it is meeting the full needs of its clients when it doesn't know who its clients really are? Additional areas of concern are: development of a program to provide home visit workers for General Assistance, Medi-Cal, and Food Stamp recipients; better promotion and greater public awareness for the In-Home Supportive Services program; sensitivity training for DSS staff and administrators; creation of the post of an independent AIDS liaison officer within the DSS, who will monitor the special needs of clients with AIDS/HIV; the need to maintain client confidentiality within the DSS; and continuation of the DSS HIV Task Force Committee.

Kent MacDonald and I will be meeting with Julia Lopez and Marilyn Chow, DSS Commission President, on November 25th. At that time we will present our list of demands to Ms. Lopez and Ms. Chow. If these demands are not met, we will plan appropriate action.

We will be meeting again with employees of the DSS at our next meeting. If you are interested in working on this issue, we urge you to attend.

ART AGNOS/FRANK JORDAN MEETINGS

Both mayoral candidates have agreed to meet with us sometime in the next week. This is an opportunity for us to attempt to become more involved with mayoral policy regarding AIDS. We discussed the option of boycotting any meetings with Frank Jordan. But there is a very strong possibility that Jordan may be the next mayor. By not meeting with Jordan and presenting our demands, we would be missing an opportunity to possibly be involved in future decisions affecting people with HIV in San Francisco. There are several areas of concern we will discuss with the candidates. They include:

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- * Appointments to the Social Services Commission and the Health Commission;
- * Membership of the Mayors HIV Advisory Task Force;
- * Budgeting for AIDS services in S.F.;
- * Expansion of medical services at the Center for Positive Care;
- * Problems with the Dept. of Social Services and the Department of Public Health;
- * Line of communication with the mayor's office;
- * Membership on the Mayor's Budget Advisory Task Force; and
- * Needle exchange program

We need input from other committees/working groups on issues they would like discussed at these meetings. Please contact someone on CHIC with your comments.

HOUSING ISSUES

Kent and Adam are working on housing issues for people with HIV. They have had several meetings with different organizations, private and city, to comprehend the current situation of housing for HIV infected people. Kent has been invited to participate on the Housing Action Committee of the Mental Health Association of S.F. If you are interested in working on this issue contact Kent or Adam and attend our next meeting.

CENTER FOR POSITIVE CARE

The next Community Advisory Board meeting is scheduled for Tuesday, Nov. 26th. The board is still attempting to form our process and fill the vacant seats. We will be examining the quality of services provided by the center and what services we believe needs to be improved/added. I will present a full report of the meeting at next week's general body meeting. Being AUGG's rep., I would appreciate any and all suggestions, comments, concerns, etc. from the general body. Please feel free to call me at either my work number (788.4999) or home number (861.5959).

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YOUTH ISSUES

Since the Youth Action Committee has disbanded, there is no committee dealing with youth issues. The lack of youth services is one of the glaring defects of the "San Francisco AIDS Model." CHIC would like to pick up where YAC left off. Unfortunately, we do not have the person power to effectively work on these issues. If you are interested in working on youth issues, come to our next meeting.

1991-92 BUDGET PROCESS

The budget process is beginning. We will be meeting with members of the Board of Supervisor's Finance Committee, heads of the Health Dept. and Social Services, and the mayor. It is very important that we receive input from members of AUGG, either from committee or general body, so that we can fight to make sure that adequate funding is provided.

CHIC meets every Thursday night, 7:00 pm, at the workspace. We encourage you to attend one of our meetings and see if you would be interested in working on local issues.

My ACTG excellent, most excellent (and sometimes bogus)
adventure by Paul Sbrizzi

Day 1

Hot and rainy. I oversleep and get to a sparsely attended CCG meeting a bit late, wearing a Women ACT UP T shirt and khaki military surplus pants.

Community Constituency Group meeting

(Comments are attributed to their makers when I remembered to write them down)

Jesse Dobson: We need a mechanism to remove people who don't do enough work from the Community Constituency Group. (What's really going on: he wants Debra Fraser-Howse, a black woman who is not at the meeting, off the committee)

David Barr: Reps from each core Committee should be on the executive committee.

Immunology Committee is looking for new surrogate markers.

The Protocol Evaluation Committee was created to pre-empt the patient care committee which was not agreeing with the Executive Committee agenda. Then the Site and Data Management Committee was created to pre-empt the Protocol Evaluation Committee.

The Cancer Institute does most of the work on Oncology, giving Oncology Committee of ACTG an identity crisis.

Neurology: Chair has been passive; infighting on committee; many ACTUs (AIDS Clinical Trial Units, the sites where ACTG trials are carried out) do not have neurologists.

Virology pushed around by primary infection committee. New virological test developed in Tom Merrigan's (member of the "Gang of Five" who control all AIDS research) lab.

Women in ACTG 019 died of liver failure: at first it was assumed they were injection drug users; but it turned out they were just given too much of the drug for their body weight. Universal exclusion of pregnant women from trials needs to be looked at.

John Fair vs. Paul Volberding for Exec. Committee Chair. (It had been assumed that Volberding was a shoo-in; this is good news)

Avg. time to get a protocol up and running: 417 days.

No mechanism for non-investigator initiated research.

Day 2

Community Constituency Group meeting

Long winded discussion about who is responsible for xeroxing protocols for community. Mark Harrington (of ACT UP New York Treatment and Data) (who is cute) doesn't have time. Will this put a terrible burden on the Division of AIDS? They seem to think so.

David Barr: The executive Committee uses Cancer as its model. This is a bad model because cancer research is slow; long-term.

Rochelle Rollins (cool person who is CCG representative on the executive committee): there is no pro-active thinking in any of the agencies dealing with AIDS. Phase 2 studies need to start getting written as soon as phase 1 trials start. All agencies should coordinate (ACTG, CPCRA, Intramurals, AMFAR). We need directed central planning of AIDS research.

Jack (Division of AIDS): Central planning is dangerous. Do we really want policies dictated by one person?

The CCG at this point decided to make a list of priorities for types of research they want to see happen.

The following suggestions were made:

- Surrogate markers
- Nesting and co-enrollment
- Wasting
- Angiogenesis/ Kaposi's Sarcoma
- Pro-active trial design
- Women
- Neurology
- Non-recognized therapies (e.g. aspirin)
- Rare O.I.'s & prophylaxis

The discussion became also about whether to prioritize and concentrate on a few of the above items (as strenuously advocated by J Dobson) or to make all-inclusive demands.

Discussion about courting pharmaceutical companies for phase 1 trials. Pharmaceuticals don't want to give up control to the ACTG. The ACTG exists to do large-scale studies.

Day 3

Oncology (Cancer) meeting

ACTG 142 (Chemotherapy for AIDS-related lymphoma) Poor recruitment. Subjects dying faster than they can be recruited. O.I.s are excluded. Also KS patients with prior chemo. Testing for dose intensity. Chemo causes O.I.s and neutropenia. Lower doses may be just as effective. Comment from researcher at back of the room: **"Don't worry about early deaths; you've got a good clean study"**.

ACTG 110 - Oral VP-16 for KS. Dose of 300 mg/wk.? Hard to say. Trying to find a schedule where it's well tolerated.

ACTG 155 Neuropathy biggest problem. 9% of patients withdrew to go to open label. Gender-specific entry criteria. No child care. Women again poorly enrolled.

Immunology meeting

CD4 changes are not considered adequate for drug licensure

Rockin' Tom Merrigan presents... A trial of Pegolated Intravenous Interleukin 2 (Peg I.L. 2 to friends) - an immuno-modulator. 1 million units every 2 weeks. 10 patients on schedule. 5 above 200 CD4 cells, 5 between 50 and 200, 1 below 50 and not responding. 30% rise in CD4 in the first week, then down to 15%. Trying triple dose in subjects above 200 CD4. "CNS" problem (a multifocal neurological problem) with 6-fold increase in dosage.

CD8 cells cultured ex-vivo (outside of patient's body) and reinfused with IL2. OIs and cancers improved in significant #s of subjects. Little if any toxicity. Leukoplakia, KS, CMV improved. \$2,000 to \$3,000 per run. Presentation looked like a minoxidil commercial, complete with before & after KS lesions.

Day 4

Women's Meeting

Need to recruit enough women, people of color, Injection drug users to get statistically significant data on these populations. 20% enrollment of women in all trials suggested as a goal.

Hemoglobin (I think this means red blood cell) criteria: have to take into account that women have a naturally lower level. A 1 point spread between levels for women and men was suggested (i.e. 9.5 for men and 8.5 for women)

Trials generally accept subjects with up to 5 times normal liver function. It was suggested that the rate of change is also important: a subject with liver function higher than acceptable (common in IDUs) may however be stable and therefore a suitable candidate for trial.

OI criteria for protocols should include women-specific OIs. Each trial should have a gynecologist assigned to it who could collect new data.

(After this we went to the plenary session and demanded to address the audience with our demands regarding ACTG 175. Larry Corey refused, saying this was about SCIENCE. Oh excuse me for having concerns about PEOPLE. The plenary session was way over my head, but I took advantage of the question and answer period to thank the researcher for his interesting presentation and then deliver our demands.)

ACTG 175 meeting

Hammer & Katzenstein (the co-chairs of this protocol) say they're going to do nested studies:

Quality of life

Women's Health

Immunology

Neurology

OIs

Pharmacology

One of the arms may be dropped depending on the outcome of ACTGs 116 and 117.

Recompetition of ACTG sites will be complete in late January or February.

Presentation on nested Quality of Life study: scary. Subjects have to share their Feelings. Eek.

Primary Infection meeting

CD4PE40 - kills HIV infected cells, but not latently infected cells. Does not cross the blood/brain barrier (large molecule). Must be administered intravenously. It did not lower T cell counts in phase 1 study (this is good). Owned by Upjohn.

GLQ223 (Compound Q) - shown to inhibit p24 antigen (measure of viral activity) in vitro. Trials starting.

NAC - In vitro data looks real good. Maybe Pentoxifyllene (?) should be added. Replenishes Glutathione. (Strains of Star Spangled Banner heard from next room as presentation concludes)

ACTG 068 - Alpha Interferon shows synergistic effect with AZT in vitro.

(At this point Jason and I notice Paul Volberding a few rows ahead, sporting a highly au courant horizontal beehive)

ACTG 143 - AZT/ddl combination therapy in asymptomatics. Not seeing significant difference in CD4 counts between combo and mono therapy.



*P. Volberding
Tan, Hot!*

The interesting thing about this meeting was that the ACTG had counted on the new class of drugs such as L drugs and BIRG to be the next wave of anti-virals, but these drugs are apparently failing due to HIV's ability to mutate around them. What emerged as most promising were the drugs derived from natural remedies, such as NAC, Compound Q.

Day 5

Return to the land of CCG

Long discussion on whether to endorse John Fair for ACTG Executive Committee president, punctuated by white males saying we don't know the candidates well enough to make an endorsement. Finally John Kimball of ACT UP/LA (an honorary non-white-male) brings up the point which in all fairness Jason had brought up the day before, that it's not so much a matter of endorsing the person as saying that we want an end to the Primary Infection Committee's stranglehold on the ACTG. CCG members get religion and endorse Fair with quite a few abstentions and one vote for Paul Volberding by SF's own Pierre Ludington.

M. Delaney: report on Phase II & III committee meeting. Too many exceptions in enrollment. Maybe have no exceptions, like CPCRA. Unblinding should be done only in life-threatening situations. Statisticians feel that CD4 and p24 are not useful predictors of disease progression. But, Delaney believes, they are still useful in evaluating drug efficacy. Percentage of CD4 is worst predictor. Best is

absolute # of white cells. However data used for these determinations is not considered very good (it was from '86 and '87).

Two combination studies are ready to go but no drugs are available. L drug and BIRG studies are continuing - supposedly because of community pressure.

Michelle Roland on Oncology. Mean T-cell count for people who get AIDS related lymphoma is around 200. Epstein Barr virus is not always a factor. Acyclovir is not working. Research is happening in parallel, not shared until it is published. Ongoing problem. Pathogenesis seems to be directly related to HIV. Cervical disease: 2 concept sheets. One went to women's health and one to Oncology. They need to be combined. Mitchell Mamen is the researcher and he refuses to take input from Oncology Committee. Starting to write protocols now for Angiogenesis drugs. Oral VP16 chemotherapy is being tolerated. Michelle is leaving CCG to concentrate on learning to be a good doctor. Much sadness amongst us all.

Gang-of five Margaret Fischl is getting very territorial in the surrogate marker working group and doesn't want John Fahey in on "her" turf.

J. Dobson: Scientists should start being graded not just on the soundness of their data but also on how many people die before they come up with something useful. Go on!

Comparison of lab data: in the 20% of labs that had the highest standard deviations (and therefore are presumably the least accurate), people with lower CD4s lived longer than people with higher CD4s. p24 antigen was a good predictor in ACTG 019 when bad (extrapolated) data was thrown out.

DHEA was a good surrogate marker for Mark Jacobson.

"Compliance" is a loaded term. There is no problem getting people to turn up at needle exchange sites. Need statistically meaningful numbers of women in ACTG 175.

Mark Harrington thinks that only the companies that make equipment for testing p24 are continuing to push for its usage. Others think it is a useful measure for viral expression specifically.

Pierre Ludington at this point said that Gay and Bisexual men have the highest rate of unsafe sex. Much furrowing of brows. He meant to say highest rate of relapse. Measured against what, I wonder.

ACTG 076: 66 women accrued. Only 20% of eligible women are electing to participate.

Adria is sitting on Rifabutin.

Syphilis trial has opened.

Want a Shot of Sunshine?

A new drug can tan the skin indoors, but don't throw out the Coppertone

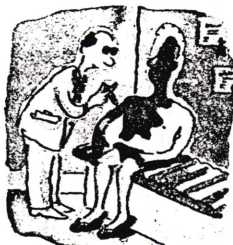
In the 70 years since Coco Chanel's bronzed mannequins helped make the perfect tan a symbol of leisure and affluence, a well-browned body seems to have joined the pantheon of inalienable human entitlements, right there alongside life, liberty and the pursuit of good TV reception. How else to explain the fuss made last week in the prestigious *Journal of the American Medical Association* about the

newest way to achieve that sun-kissed look: by injection.

In a seven-page report, with accompanying editorial, a team of scientists led by University of Arizona dermatologist Norman Levine told how, in a randomized, placebo-controlled experiment, visible tanning was induced in 15 healthy men after 10 injections of a potent hormone called MSH (melanocyte-stimulating hormone). The tans lasted nearly nine weeks with no immediate side effects beyond a brief flushing sensation and a mild stomachache.

But it's hard to imagine sun worshippers lining up at doctors' offices for

their bimonthly tanning fix. No one should take any hormone without considering the long-term consequences. And as the *J.A.M.A.* editorial points out, MSH is a powerful brain chemical associated with a wide range of neurological effects; it is known to influence verbal memory in humans and sexual behavior in rats. Levine and his colleagues argue that tanning shots might offer protection for fair-skinned patients who sunburn easily, a group increasingly at risk for skin cancer as the ozone layer shrinks. But is that anything that can't be achieved at lower cost and less danger with a smear of sunscreen and a wide-brimmed hat? ■



GARY ZACHARICH FOR TIME

ACT UP GOLDEN GATE

PROACTIVE, NON-DISCRIMINATION POLICY
FOR DRUG AND HEALTHCARE COMPANIES

IT IS THE OFFICIAL POLICY OF ACT UP GOLDEN GATE TREATMENT ISSUES COMMITTEE TO ENCOURAGE PHARMACEUTICAL AND HEALTHCARE COMPANIES SERVICING THE HIV INFECTED COMMUNITY TO ADOPT FORMAL POLICIES AND PROACTIVE PROGRAMS TO FORESTALL DISCRIMINATION IN HIRING, PROMOTION AND THE WORKPLACE AGAINST PEOPLE WITH HIV AND AGAINST ANY PERSONS ON THE BASIS OF THEIR SEXUAL ORIENTATION AND LIFESTYLE PREFERENCE.

WE BELIEVE IT IS NOT ONLY JUST, FAIR AND REASONABLE BUT GOOD BUSINESS AS WELL, THAT FIRMS WHO DERIVE SUBSTANTIAL INCOME FROM THE HIV INFECTED, GAY AND LESBIAN COMMUNITIES AND SERVICE MANY OF OUR PEOPLE SHOULD UNDERTAKE SPECIAL EFFORTS, SUCH AS ADOPTING FULL DOMESTIC PARTNER BENEFITS, TO CREATE A WORKPLACE ENVIRONMENT WHERE THE HIV INFECTED, GAYS, LESBIANS, BISEXUALS AND HETEROSEXUALS ARE ALL EQUALLY WELCOME, AND WHERE PEOPLE OF BOTH SEXES AND ALL RACES CAN FEEL COMFORTABLE BEING THEMSELVES WITHOUT EVER NEEDING TO HIDE THEIR HIV STATUS OR THEIR SEXUAL ORIENTATION AND LIFESTYLE PREFERENCES.

April 29, 1992

To ACT UP San Francisco General Body:

It has now been a couple weeks since the General Body came to consensus on a "budget" for the VIII International Conference on AIDS this July in Amsterdam and it has been about a month since the Immigration Working Group's proposal was presented and acted as a catalyst to planning for the conference. During all this time I have been carefully monitoring my feelings and thoughts on the process and the outcome of the "budget" discussions and now must respectfully resubmit the Immigration Working Group's original proposal for consensus.

First, though, I feel I need to describe the context within which all this is happening for me. I work at the Gay Asian Pacific Alliance Community HIV Project (GCHP) - a mostly gay and all Asian HIV/AIDS service provider. What I have noticed about myself and my behavior is that I act differently when I am at GCHP and when I am at ACT UP. More likely than not, I am much more "polite" and "reserved" at ACT UP and I have come to see that this is so for two major reasons.

One is that when I first started working with ACT UP, specifically with the Immigration Working Group - which was before I began working with GCHP, I felt that everyone around me knew so much more than I did and that I had a great deal of "catching-up" to do. I was very excited and happy with the prospect of being, in effect, back in school -- activist school. I was learning and continue to learn by listening and by being involved in tasks.

The second reason for my "reserve," relative to how I am in the GCHP/Asian context, is now becoming more clear to me. That is, when I am not in a gay Asian environment I do not feel empowered to be who I am, respond how I normally respond when I trust that people will understand...internalized racism if one wants to use the lingo.

So what am I trying to get at here and why am I going to all the trouble to write this all down? Would I write such a document for my queer Asian peers? Obviously, not -- it wouldn't be necessary. I am writing this down firstly to organize my own emotionally loaded thoughts and secondly because I believe that by giving people a written statement I am taking a more active step in telling my story in a way that can be more readily revisited and digested. (UNIVERSE!! the lengths I am going to make this easy for you all to understand!!!)

Any way, to be very blunt -- as this Aries Tiger, moon-in-Leo, Aquarius rising, kimchee eating, korean american fag -- can be. I am really pissed-off that the Immigration Working Group (IWG) was "punished" for having a plan ready to go as soon as it was evident that Red Hot and Blue money was available.

To support the "politic" but not the expenditure of money - and I am sorry if the use of this analogy offends anyone - makes me think of the Ryan White CARE act made stupid and powerless for lack of funding.

How many times must the IWG remind people that we are the ONLY group of people in this country working on the abolishment of the blah-blah-blah...you know what I am talking about. How many times must we point out how important it is to activists in other countries that we keep up the pressure on all fronts? Without the activist work done by ACT UP in the U.S. activists in other countries have that much less leverage and inspiration to do their work, to attack their systems of oppression.

Why do we look at this Red Hot and Blue money as some treasured golden egg which we will eke out over as many demonstrations and years as possible? Why not look at this boon as an inspiration and resource with which to make more money?

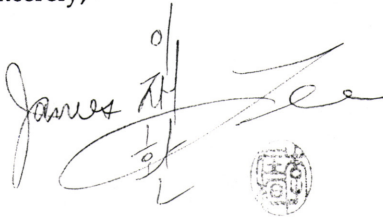
The Amsterdam budget as approved is actually fine as far as I am concerned except for the part about "contingent upon fund raising." What the hell does that mean and how is anyone supposed to plan travel, accommodations, political strategy when the money is "contingent upon..." and not COMMITTED?

Can't we commit to the expenditure of money for Amsterdam AND commit to the fund raising?

And, this I've mentioned before -- I am not all together satisfied with the sketchy commitment the General Body has made to fund raising in Amsterdam. Do any of you realize how much work it actually takes to coordinate the selling of merchandise?

Well, I could rant and rave for pages and that wasn't what I intended to do by writing, so, I will stop here and we'll have it our verbally I suppose. Challenge me, question me, but don't expect me to be the nice, polite Asian any more.

Sincerely,

A handwritten signature in cursive script, appearing to read "James H. Lee". The signature is written in dark ink and is somewhat stylized, with a large loop at the end. Below the signature, there is a small, circular, embossed or stamped mark that is partially obscured by the ink.

ACT UP!

amsterdam

Act Up! Amsterdam

Postbus 15452

1001 ML Amsterdam

telephone: +31.20.639.2522

fax: +31.20.██████████ 6230680

17 March 1992

To all Act Up! groups
attention: "Amsterdam Working Groups"

subject: accommodation during international conference July '92

Greetings from Amsterdam,

As you probably know, the 8th International AIDS Conference is being held in Amsterdam from 19-24 July 1992. There will also be satellite conferences from around 14 July till 26 July.

We recommend that your group makes hotel reservations immediately, as during mid-summer everything here will be booked out. Enclosed is a list of Amsterdam's cheaper hotels and camping grounds. To make reservations, you can contact the Dutch National Reservation Centre, Postbus 404, 2260 AK Leidschendam, The Netherlands, tel. +31.70.3202500; fax +31.70.3202611, telex 33755 who will make bookings and arrangements for you.

Act Up! Amsterdam will try to provide accommodation in private homes for at least some members of Act Up! from other countries. We will try to help Act Up! groups who have little money first, and then a certain percentage from each group having access to more funds.

So we need to know:

--how many members of your group plan to come to Amsterdam (either to attend the conference itself or to help with the Act Up! actions and meetings)

--date(s) of arrival in and departure from Amsterdam

--do some people attending have special accommodation needs or requests (women-only space, wheelchair access, lots of rest, non-smoking space, no cats, not too many stairs - Amsterdam is full of tiny and steep staircases up to four floors high -etc)

--some people providing accommodation specify that they would prefer to accommodate women or men/lesbians or gays/non-smokers/....etc./. If you think it's relevant to give these details, or if you would like to specify which people you would prefer to stay with, please include these details in your reply if possible.

Procedure

We need a written reply (fax is ok too) from your group before May 10th.

If you reply before this date, we will send a letter of confirmation as soon as possible.

Transport in Amsterdam

The venue for the conference, "de RAI", can easily be reached by sneltram 51 (wheelchair accessible) and tram 4 (not wheelchair accessible). The venue is not far from the city centre, but taxis

are expensive here. Car parking space at de RAI is 10 guilders per day. Public transport maps are widely available. Bicycles could also be an option for some.

Even if you do not need help with accommodation, we need to know the names of people coming to Amsterdam and their specific field(s) of interest (within Act Up). This will help us in planning Act Up! meetings around the conference, and in networking.

Thanks for your help
and see you in July!

the accommodation working group
Act Up! Amsterdam

List of Hotels

★ The standard of comfort and the facilities available are expressed by means of stars. This brochure is based primarily on the official valuations issued by the relevant authorities (Benelux Hotel Classification, Industrial Catering Board).

- prices excluding breakfast
- ♿ accessible to wheelchair users
- ♿ accessible to wheelchair users with helper
- ▲ A participant in arrangement "Winter, the Amsterdam way" (category A-E)

- ✉ address
- PC post code
- ☎ telephone
- ↑ number of rooms
- ↗ number of rooms with bath
- ≡ number of beds (sleeping places)
- ! single room (price in guilders)
- ≡ double room (price in guilders)
- ✕ restaurant:
○ = yes
-- = no
- ℳ elevator:
○ = yes
-- = no

- ✎ pets allowed:
○ = yes
-- = no

- Ⓐ apartment:
○ = yes
-- = no

- Ⓔ credit cards accepted:
○ = yes
-- = no

PRICES:
the prices mentioned are high season prices as these were known to vvv AMSTERDAM TOURIST OFFICE at the time they appeared in this brochure (November 1991). There are special tariffs for other seasons. Enquire for "special arrangement" prices. The prices apply as from 1.1.92, and are valid per room, including breakfast, service and taxes, but are subject to alteration.

★ ★ Comfortable hotel	✉	PC	☎	≡	↑	↗	!	≡	✕	ℳ	✎	Ⓐ	Ⓔ
Van Acker	J.W. Brouwersstraat 14	1071 LJ	6790745	23	12	5	50/ 55	110/120	-	-	-	-	-
Acro	Jan Luykenstraat 44	1071 CR	6620526	120	51	51	100	135	-	○	-	-	○
Agora	Singel 462	1017 AW	6272200	27	14	11	98/150	105/180	-	-	○	-	○
Amstel Botel Hotel	de Ruyterkade pier 5	1011 AA	6264247	95	46	39	57	72/ 82	-	-	-	-	-
Amstelzicht	Amstel 104	1017 AD	6236693	21	12	4	60/ 95	90/195	-	-	-	-	○
Amsterdam Wiechmann	Prinsengracht 328-332	1016 HX	6263321	77	36	36	135/150	175/200	-	-	○	-	-
D'Amsterdam	Tweede Heimerstraet 4	1054 CH	6160125	32	16	8	65/ 75	95/105	-	-	-	-	-
Apple Inn	Koninginneweg 93	1075 CJ	6627894	45	20	4	50/ 65	75/145	-	-	-	-	○
Armada	Keizersgracht 713-715	1017 DX	6232980	61	27	20	110/155	125/165	-	-	○	-	○
Arsenal	Frans van Mierisstraat 97	1071 RN	6792209	25	11	6	-	95/140	-	-	-	-	-
Asterisk ▲ D	Den Texstraat 16	1017 ZA	6262396	43	19	14	60/ 85	75/149	-	*)	○	-	○
Bodeman	Rokin 154-156	1012 LE	6201558	35	17	17	100/125	135/175	-	-	-	-	○
Van Bonga	Holbeinstraat 18a	1077 VB	6625218	28	17	11	75/ 90	120/135	-	-	-	-	-
Casa-Cara	Emmasstraat 24	1075 HV	6623135	24	9	6	50/ 80	70/ 95	-	-	-	-	-
Central Park West Hotel	Roemer Viisschersstraat 27	1054 EW	6852285	27	11	7	55/ 65	85/135	-	-	-	-	○
Cynthia	Vondelstraat 44-48	1054 GE	6188553	97	43	45	110	140	○	-	-	-	○
City Hotel	Prins Hendrikade 130	1011 AP	6230836	50	21	7	65/ 85	115/165	○	-	-	-	○
Destiné	Sarphatide 17	1017 WV	6236822	24	9	5	80/ 95	95/115	-	-	-	-	-
Engeland	Roemer Viisschersstraat 30a	1054 EZ	6129691	65	27	13	60/115	105/155	-	-	○	-	○
De Filosoof ▲ D	Anna Vondelstraat 4-6	1054 GZ	6833013	54	25	18	90/165	110/175	-	-	○	-	○
Fita	Jan Luykenstraat 37	1071 CL	6790976	38	17	15	90/130	100/175	-	-	-	-	○
Freeland	Marnisstraat 386	1017 PL	6227511	40	17	13	70/ 90	95/150	-	-	-	-	○
Friendship	Van Eeghenstraat 22	1071 GG	6644011	23	15	15	85	145	-	-	-	-	○
Groenhof	Vondelstraat 74	1054 GN	6168221	60	30	22	75/105	110/145	-	-	○	-	○
Imperial	Thorbeckeplein 9	1017 CS	6220051	36	18	15	90/130	120/175	-	-	-	-	○
ITC (gay)	Prinsengracht 1051	1017 JE	6230230	19	15	10	75/ 88	135/160	-	-	-	-	○
Jupiter ▲ E	Tweede Heimerstraet 14	1054 CJ	6124964	30	12	8	75/130	95/140	-	-	○	-	○
De Gouden Ketting	Keizersgracht 268-272	1016 EV	6248287	38	20	19	75/110	110/150	-	-	-	-	○
De Korenaer	Damrak 50	1012 LL	6220855	41	23	23	75/ 85	99/135	○	○	-	-	-
Middelberg	Koninginneweg 149	1075 CM	6765392	32	12	8	-	100/140	○	-	-	-	-
De Munck	Achtergracht 3	1017 WL	6236283	24	9	6	80/ 90	110/160	-	-	○	○	-

**★ Comfortable hotel	✉	PC			?	↑	↓		X	↺	↻	A	E
New York (gay)	Herengracht 13	1015 BA	6243066	25	17	15	85/235	140/275	-	-	-	-	-
Sint Nicolaas	Spuistraat 1a	1012 SP	6261384	56	24	24	99/100	126/135	-	-	-	-	-
Omega	Jacob Obrechtstraat 31	1071 KG	6645182	29	15	11	80/140	95/165	-	-	-	-	-
Parklane	Plantage Parklaan 16	1018 ST	6224804	22	11	9	65/115	135/155	-	-	-	-	-
Parkzicht	Roemer Visscherstraat 33	1054 EW	6181954	27	15	12	55/85	125/145	-	-	-	-	-
Piet Hein	Vosiusstraat 53	1071 AK	6628375	55	26	26	80/110	115/155	-	-	-	-	-
Int. Police Hotel	Voorburgstraat 250	1059 VD	6157026	82	35	35	85	140	-	-	-	-	-
De La Poste	Reguliergracht 3-5	1017 LJ	6237105	36	15	15	120/140	140/200	-	-	-	-	-
The Golden Regal	Korte van Eggenstraat 8	1071 ER	6762131	25	13	6	70/80	100/110	-	-	-	-	-
Rembrandt	Plantage Middenlaan 17	1018 DA	6272714	25	13	7	70/95	95/135	-	-	-	-	-
La Richeile	Holbeinstraat 41	1077 VC	6717971	15	6	6	125	175	-	-	-	-	-
Rokin	Rokin 73	1012 KL	6267456	80	36	23	55/115	75/130	-	-	-	-	-
Savoy	Michelangelostraat 39	1077 BR	6790367	50	26	19	80/105	100/135	-	-	-	-	-
Sipermann	Roemer Visscherstraat 35	1054 EW	6161866	21	13	5	60	90/135	-	-	-	-	-
Stadhouders	Stadhouderade 76	1078 AE	6718428	45	19	10	65/85	95/135	-	-	-	-	-
Thorbecke	Thorbeckeplein 3	1017 CS	6232601	22	12	8	50/65	80/150	-	-	-	-	-
Verdi	Wanningstraat 9	1071 LA	6760073	29	12	6	70/120	90/150	-	-	-	-	-
Vijaya	O.Z. Voorburgwal 44	1012 GE	6269406	35	16	16	85	110	-	-	-	-	-
The Village	Kerkstraat 25	1017 GA	6269746	22	10	10	75/95	95/125	-	-	-	-	-
Vullings	P.C. Hoofdstaat 78	1071 CB	6712109	25	11	7	80/100	95/120	-	-	-	-	-
The Waterfront	Singel 458	1017 AW	6239775	15	8	8	125/145	175/195	-	-	-	-	-
Wilhelmina	Koninginneweg 167-169	1075 CN	6640594	45	19	13	55/135	85/155	-	-	-	-	-

^{a)} elevator as from April 1st, 1992

* Plain but comfortable hotel		PC																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																
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★ Plain but comfortable hotel		PC																	
De Westertoren Wijn Nobel	Raadhuistraat 35 Vossiusstraat 9	1016 DC 1071 AB	6244639 6622298	15 30	8 12	4 1	40/ 45 60/ 70	70/ 85 90/100	— —	— —	— —	— —	— —	— —	— —	— —	— —	— —	— —
No classification		PC																	
Beursstraat • La Bohème • Brian Damhotel Florence	Beursstraat 7 Marnixstraat 415 Singel 69 Damrak 31 Van Eggenstraat 44	1012 JT 1017 PK 1012 VE 1012 LJ 1071 GJ	6263701 6242828 6244661 6240945 6793798	61 29 34 54 9	38 18 14 21 5	2 — — 21 2	— 35/ 40 40 75/250 49	50/ 55 70/ 80 80 110/350 85	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	
Hotel 83 Van Huissen De Bloeiende Ramen The Regal (facts 1991) San Luchas (ecumeni)	O.Z. Achterburgwal 83 Bloemgracht 108 Haarlemmerdijk 61 Binnen Wieringerstraat 9 Waldeck Pyrmontlaan 9	1012 DC 1015 TN 1013 KB 1013 EA 1075 BT	6262089 6265801 6246030 6274390 6716861	32 20 23 25 40	15 8 9 11 25	11 — — — 25	60 50 — 50/ 60 40/ 45	120 100 80 70/ 90 80/ 90	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	
Senova Dinar The Veteran	Frederiksplein 15 Herengracht 561	1017 XK 1017 BW	6206425 6202673	4 25	4 10	— 4	75/ 85 —	— 80/125	— —	— —	— —	— —	— —	— —	— —	— —	— —	— —	— —

Youth hotel		PC																	
Adam & Eva • Aroza • Bob's Youth Hostel Hans Brinker Eben Haëzer	Sarphatistraat 105 Nieuwendijk 23 N.Z. Voorburgwal 92 Kerkstraat 136 Bloemstraat 179	1018 GA 1012 LZ 1012 SG 1017 GR 1016 LA	6246206 6209123 6230063 6220687 6244717	78 31 160 255 114	6 10 16 30 6	— 10 16 — 4	— — — 67/86 —	— 120 — 103/139 —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —
Kabul • Keizersgracht • Jeugdhotel Meeting Point • The Shelter Stadsdoelen (IVHF)	Warmoesstraat 38-42 Keizersgracht 15 Warmoesstraat 14 Barnesteeg 21 Kloveniersburgwal 97	1012 JE 1015 CC 1012 JD 1012 BV 1011 KB	6237138 6251364 6277499 6253230 6246832	170 83 80 166 184	39 26 8 8 9	25 16 — 8 —	60 50 — — —	65/85 85 — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —	— — — — —
Vondelpark (IVHF) Sleep-in Maatskade • & Zeezicht	Zandpad 5 s Gravesandestraat 51 Piet Heinkade 15	1054 GA 1092 AA 1019 BR	6831744 6947444 6178706	300 550 30	40 16 12	— — 6	— — —	45 — —	— — —	— — —	— — —	— — —	— — —	— — —	— — —	— — —	— — —	— — —	— — —

*) Dormitory

Camping	✉	PC	☎	*)	**)	***)	****)
Het Amsterdamse Bos	Kleine Noordijk 1/Aalsmeer	1432 CC	020-6416868	○	○	7.20	01-04/30-10
De Badhoeve	Uitdammerdijk 10/Amsterdam	1026 CP	02904-294	○	○	8,—	01-04/31-10
Gaasper Camping	Loosdrechtse 7/Amsterdam	1108 AZ	020-6967326	○	○	8.35	01-01/31-12
Vliegenbos	Meeuwenlaan 138/Amsterdam	1022 AM	020-6368853	○	○	5.50	01-04/30-09
Zeeburg	Zuider IJdijk 44/Amsterdam	1095 KN	020-6944430	—	○	6,—	01-04/30-10
*) fam. **) youth *** price p.p. + tent **** open							

*) fam. **) youth ***) price p.p. + tent ****) open

Apartments	✉	PC	🚗	🏠		✉	PC	🚗
Amsterdam Apartments	Kromme Waal 32	1011 BV	6265930	C1	Holbein Studio's	Holbeinstraat 5	1077 VB	6628832
Amsterdam House Apartments	Staalakade 4	1011 JN	6262577	C2	I.D.A. Housing Services	Den Texstraat 30 hs	1017 ZB	6246301
Canal Apartments	Nieuwe Achtergracht 67	1018 WL	6257238	D2	Internity Room Service	Van Ostadestraat 348	1073 TZ	6750064
Briefcase Home Tip	Sarphatistraat 116-118	1018 GW	6254443	D2	Riverside Apartments	Amstel 138	1017 AD	6279797
Gasthuismolen Apartments	Gasthuismolensteeg 10	1016 AN	6240736	C1	Toff's Apartments	Ruysdaelkade 167	1072 AS	6738529
G.I.S. Apartments	Keizersgracht 33	1015 CD	6250071	C2				

Hotels with apartment facilities: see hotelist above II

RESERVATION COUPON

Total number of persons: Children under 3 years of age: and 4 to 11: Date of arrival: Date of departure: Number of rooms: Number of nights: 1st choice hotel: 2nd choice hotel: ☐ with ☐ without ☐ bath ☐ shower ☐ toiletPrice in NLG per person per day

Complete in block capitals and send to: Nationaal
Reserverings Centrum Nederland, Postbus 404,
2260 AK Leidschendam, Nederland.
For reservations by telephone please see page 27.

When booking the special arrangement "Winter, the
Amsterdam way" (see page 27), please circle the desired
category of hotel: ☐ A ☐ B ☐ C ☐ D ☐ E

Name Street Post code Town or City Country

AIDS AND THE NEXT PRESIDENT

A Five Point Platform

July 1992
**United
For
AIDS
Action**

AIDS HAS KILLED SO MANY SO QUICKLY

because of all the epidemics that underlie it: an epidemic of homelessness, an epidemic of drug and alcohol addiction, and epidemic discrimination on the basis of race, sex and sexual orientation. Fueled by poverty, AIDS is spreading fastest in the communities that have least access to health care and education — particularly communities of color.

We cannot end the AIDS crisis without making a commitment to end the crises that keep it growing. Nor can we ignore the specific demands that the AIDS epidemic now places on the highest elected official in this country.

We call on the next President to adopt the following five-point platform:

- More Americans have died of AIDS than died in the Gulf, Vietnam and Korean wars combined.
- 213,000 Americans have now been diagnosed with AIDS and more than 138,000 have died. More than one million Americans are estimated to be infected with HIV. (Centers for Disease Control)
- The first 100,000 cases of AIDS in the U.S. were diagnosed in the first eight years of the epidemic. The next 100,000 cases were diagnosed in less than three years. Another 100,000 will be diagnosed in less than 12 months. (CDC, National Commission on AIDS)
- As many women as men will be diagnosed with AIDS worldwide by the end of the decade. (CDC)
- 46% of Americans with AIDS are people of color. Three out of four American women with AIDS are women of color. (CDC)
- 10 million AIDS cases are expected worldwide by the year 2000. 40 million men, women and children will be infected with HIV. (World Health Organization)

1 LEADERSHIP. The next President must lead the nation by saying five words — “America declares war on AIDS” — and stand by that declaration in word and deed.

Leadership means breaking the Presidential silence on AIDS. We heard no outcry from the White House when Congress slashed the amount of emergency AIDS relief provided by the Ryan White CARE Act. Where are the President's public service announcements about AIDS, and the Surgeon General's mailings about HIV prevention? We are still waiting for the Presidential candidates — including the incumbent — to commit themselves to implementing the 30 recommendations made by the National Commission on AIDS in 1991.

Our nation's leader can and should be a forceful Commander-in-Chief in the worldwide battle against AIDS, fighting discrimination and mobilizing resources for AIDS education, research and care.

AIDS LEADERSHIP is crucial because:

- The majority of Americans believe the Federal Government could and should be doing more about AIDS. (Roper poll, 1991)
- It took President Reagan six years, and 40,000 AIDS deaths, to say the word AIDS in public.
- President Bush has devoted only one public speech to AIDS.
- The Ryan White CARE Act, authorized to provide \$881 million in emergency relief to the sixteen cities hardest hit by AIDS, was funded by Congress at less than a third of that amount for 1991. President Bush remained silent.

2

AIDS CARE. The next President must come forward with a single payor universal health care plan that covers everything, including prescriptions and preventive care. As AIDS cases increase, so must funding for AIDS services, including funds for housing, drug treatment and community-based AIDS organizations.

New AIDS treatments are only useful if people have access to the health care system that controls them. But an estimated 37 million Americans do not have the insurance — either private health insurance, Medicaid or Medicare — that they need to get care. Public emergency rooms force people to wait for days for a hospital bed. Public clinics are not able to see new patients for months. Private doctors refuse to accept Medicaid, on which 40% of Americans with AIDS rely. Partial reforms offer only partial solutions. Only a complete overhaul of the system — a universal health care plan — can guarantee Americans the needed services.

AIDS care is not just hospital beds. It is services for people with all stages of HIV illness. It is medically appropriate housing for the tens of thousands of Americans with HIV who are homeless. It is a range of accessible substance abuse services for the hundreds of thousands of drug and alcohol users currently kept at arm's length from treatment. It is the provision of food and services to combat malnutrition, as well as the advocacy and case management performed by AIDS organizations across the country. Many of these organizations, though they use volunteers to make every dollar go farther, are given no funding increases even as their annual caseloads go up by as much as 300%.

3

RESEARCH. The next President must fight AIDS the way America fought polio or ran the space race: with intensive research. He must commit funds to finding a cure for HIV and the immune damage it causes, drugs to prevent and treat AIDS-related infections, and a vaccine to protect the uninfected.

There are only two approved drugs — AZT and ddI — that attack HIV directly. Both are highly toxic, and neither has proved successful in halting the virus's destruction of the immune system. Basic research on how HIV progresses to AIDS has yet to be done. The handful of drugs approved to combat AIDS-related infections are inadequate and expensive — one costs \$21,000 a year wholesale. Experimental AIDS drugs are tested in clinical trials that remain largely inaccessible to women, intravenous drug users, people of color and people in rural areas. Holistic and alternative therapies are often not tested at all.

AIDS CARE is crucial because:

- Almost one third of all urban AIDS patients, have no public or private health insurance. (National Commission on AIDS)
- More than 100,000 children will have lost one or both parents to AIDS by the end of this decade. (The New York Times)
- Public hospitals around the country report emergency room waits of up to ten days, and run an average annual deficit of over \$9 million. (National Association of Public Hospitals, 1991)
- The Federal government proposes spending eight times more for new prison beds than for new drug treatment slots in 1992. New York State has the capacity to treat less than 10% of its 550,000 substance abusers. (National Commission on AIDS, Health Systems Agency)

AIDS RESEARCH is crucial because:

- The median survival for people diagnosed with AIDS after 1987 is still less than two years. (New England Journal of Medicine, 1991)
- By next year, AIDS will have outstripped all other diseases in terms of lost productivity, causing close to 3 million years of potential life and billions of tax dollars to be lost. (National Commission on AIDS, Washington Post and Public Health Report)
- Nearly nine in ten Americans believe that more government funds for research would help end the AIDS epidemic. (Roper Poll, 1991)

Pitting AIDS funding against research dollars for other diseases misses the point. AIDS is an infectious epidemic that is increasing exponentially, and more dollars should be going toward research of *all* health care problems. Politicians may say we cannot afford to spend more, but we cannot afford *not* to.

4

EDUCATION. The next President must deliver AIDS education that works. He must support targeted, honest HIV prevention campaigns for all communities.

He must expand HIV treatment education for both patients and providers.

Prevention education is the only vaccine we have against AIDS, and we are not using it effectively. Close to one fifth of all adults with AIDS appear to have been infected during adolescence, yet many public school systems have no AIDS curriculum at all. Though needle sharing accounts for the fastest rising rates of HIV infection, many cities offer no education or materials to help drug users reduce risks to themselves or their sexual partners. Instead of targeted, realistic education campaigns, the Federal government has emphasized "Just Say No" campaigns and refused to fund the honest educational materials that work best. Nor is AIDS information enough — we need long-term programs to help Americans maintain lifesaving behavior.

Treatment education can get Americans with HIV the information and the drugs they need to stay healthy. More than 20,000 Americans were diagnosed last year with PCP, an AIDS-related pneumonia that is now preventable. Regular T-cell testing and PCP prevention have not been integrated into drug treatment or prison settings. Many health care providers have never been trained to diagnose and treat HIV related illness, particularly in women who get different symptoms and infections than men.

AIDS EDUCATION is crucial because:

- Half of all teenagers have sex by age 17. (CDC)
- 98% of Americans say they need more information about where to go for help if exposed to HIV. (Roper Poll, 1991)
- Women with AIDS, often misdiagnosed or unaware that they are at risk, die two times faster than men. (Pat Closer, VI & VII International Conference on AIDS)
- It is ten times cheaper to prevent the pneumonia that is the leading killer of people with AIDS than it is to treat that pneumonia. (Journal of the American Medical Association, Public Health Reports)

5

DISCRIMINATION. The next President must show that mandatory testing and HIV-related discrimination are unAmerican and unacceptable. He must fully implement the Americans with Disabilities Act and speak out against policies that bar people with HIV from insurance coverage, employment, housing, Federal benefits and entrance into the country.

HIV testing should be voluntary and anonymous, not a means of social control. Yet private insurers regularly test Americans for HIV and deny coverage to those who test positive. Mandatory HIV testing is currently enforced in the Federal Job Corps program, the military, and Federal prisons.

U.S. immigration authorities can deny entry visas to people who are HIV positive. Federal and state laws limit women's information about and access to reproductive health care. The rigid AIDS definition used by the Federal Centers for Disease Control ignores common manifestations of HIV disease in women and intravenous drug users, causing many Americans disabled by AIDS to be denied services and financial support.

AIDS DISCRIMINATION protection is crucial because:

- Almost one in three physicians surveyed in 1991 see nothing wrong with refusing to treat HIV positive patients. (Journal of AMA)
- One third of all Americans under age 65 have conditions that health insurance companies can use as an excuse to raise premiums or deny coverage. (Guzen Action, 1991)
- Calls for mandatory testing of health care workers continue, in spite of evidence showing that the odds of surgeon-to-patient transmission of HIV are one in 21 million. (New England Journal of Medicine)

WE ARE SERVICE ORGANIZATIONS and health care providers, church groups and women's organizations, housing and hospital workers, lobbyists and community organizers and volunteers. We represent voters who are Black, White and Latino, Native American, Asian and Pacific Islander. We are mothers and fathers, drug users and their sexual partners, lesbians, gay men, bisexuals and heterosexuals, people with HIV and people who care about them. For all our differences, we all agree on a single, unignorable point:

The AIDS crisis is just beginning.

**United
For
AIDS
Action**

SEND OUR MESSAGE TO DEMOCRATS AND REPUBLICANS!

**Join thousands at the AIDS Unity March and Rally,
Tuesday, July 14.**

**Call 212/337-1227 for information, or write to
175 Fifth Ave. Suite 2179, New York, NY 10010**

UNITED FOR AIDS ACTION is a coalition of AIDS & Adolescent Network • AIDS Action Council • AIDS Coalition To Unleash Power (ACT UP)/New York • AIDS Interfaith New York • AIDS Resource Center • American Indian Community House • Asian and Pacific Islander Coalition on HIV/AIDS • Association for Drug Abuse Prevention and Treatment (ADAPT) • ARRIVE • Black AIDS Mobilization • Black Leadership Commission on AIDS • Body Positive • Broadway Cares • Brooklyn AIDS Task Force • Bronx AIDS Services • Community Family Planning Council • Community Health Project • Dignity USA National AIDS Project • East Harlem Settlement AIDS Program • East New York HIV Project • Empire State Pride Agenda • Equity Fights AIDS • Family Health Project • Funders Concerned About AIDS • Gay Men of African Descent • Gay Men's Health Crisis • God's Love We Deliver • Haitian AIDS Coalition • Hetrick-Martin Institute • High School HIV/AIDS Resource Center • Hispanic AIDS Forum • Housing & Services, Inc. • Housing Works • Human Rights Campaign Fund • Jewish Board of Family and Children's Services • Lambda Legal Defense & Education Fund • Latino Commission on AIDS • Legal Action Center • Life Force: Women Fighting AIDS • Manhattan Plaza AIDS Project • MFY Legal Services/HIV Project • Minority Task Force on AIDS • Mothers' Voices Campaign • Ms. Foundation for Women • National Association of Religious Women • New York AIDS Coalition • Partnership For The Homeless • Positive Action Of New York • Promesa, Inc. • People With AIDS Coalition • People With AIDS Health Group • Senior Action in a Gay Environment (SAGE) • South Asian AIDS Action • South Brooklyn Legal Services/HIV Unit • South Bronx Neighborhood AIDS Project • STAND UP/Harlem • Staten Island AIDS Task Force • Treatment Action Group • Upper Room AIDS Ministry • Village Nursing Home • Visual AIDS • Women and AIDS Resource Network • Women in Need • Women's Action Coalition (WAC) • Women's Health Action and Mobilization (WHAM!) • Women's Health Education Project • Women's Prison Association • Young Adult Institute

c. 1992

**Council on Competitiveness
Reforms for Improving the Nation's Drug Approval Process**

A Statement by AIDS Activist Organizations & AIDS Service Organizations

***** Draft *****

On November 13th the White House issued from its Council on Competitiveness, chaired by Vice President Dan Quayle, its 11 point reform plan of the Food & Drug Administration and the U.S. drug approval system. We immediately began to see certain interest groups and politicians line up behind either consumer protectionist or deregulationist demagoguery, democratic party line or republican party line. We would like to encourage everyone participating in this process to focus on the issues or specific reforms outlined in the 11 point plan and to resist the temptation to make this a partisan debate or an insiders' ritual battle.

The White House proposals are largely based on the "Lasagna Report" (Final Report of the National Committee to Review Current Procedures for Approval of New Drugs for Cancer and AIDS, released August 15, 1990), which was widely acclaimed in the AIDS community. For many years the AIDS community has pleaded with the White House to show leadership in the epidemic. Now Vice President Quayle has put his name on proposals which, had they come instead from the traditional friends of the AIDS community in Congress, might well have achieved greater acclaim. The new proposals actually go beyond the 1990 recommendations in that they would change procedures for all drugs, not just those required for the treatment of life-threatening conditions.

The purpose of this statement is to assemble the views of various AIDS activist and service organizations into a consensus statement, and where there is not clear consensus to present the issues surrounding the particular reform.

Reform No. 3 — Expanded Role for Institutional Review Boards

This reform would "permit sponsors of new drugs to submit their applications for Investigational New Drugs (INDs) involving Phase I studies of patients for commercial drugs and all IND's for non-commercial drugs to the appropriate Institutional Review Board (IRB) for approval and will not require additional agency review....At present, both FDA and the IRB must review such Investigational New Drugs (INDs)."

Argument in Favor of this Reform:

Many lives are lost because of missed opportunities early in the drug development process, largely outside of public view. Many promising AIDS treatments are routinely delayed for years for purely commercial and regulatory reasons (e.g. hypericin, peptide T, and N.A.C.). Others have come into use by thousands of people without being tested (e.g. AL 721, dextran sulfate, and DNCB) because no drug company had the incentive and the resources to move quickly. The current system usually requires hundreds of thousands of dollars for animal and other preclinical tests before a trial can ever begin, even for a drug already used by thousands of people elsewhere; only the best-financed corporations or government agencies need apply. The fatal catch-22 is that these large organizations are slow to move when there is no human data on the potential treatment use.

This proposal would open the process to smaller companies, universities, physicians' organizations, and community agencies — allowing entry by those whose bottom line is saving lives, not corporate profits or professional politics or careers. These smaller organizations could quickly test promising leads, giving critically important treatment advances the early attention and credibility they need. Any which showed dramatic results would almost certainly be followed up quickly, even under existing arrangements.

Argument Opposed to this Reform:

Reform No. 4 — Flexible Interpretation of the Efficacy Standard.

The White House proposal says that the "FDA will make a deliberate effort to interpret the statutory requirement of efficacy in a manner that maximizes rather than limits a drug's potential for approval and takes into account the risks — to human life and health that may result from delay of new treatments....FDA will use flexibility in the current statute to develop and adopt surrogate endpoints whenever possible to measure the efficacy of drugs used to treat life-threatening diseases."

Consensus Statement:

The use of surrogate endpoints as substantial evidence of a drugs efficacy in the treatment of life-threatening illness has long been favored by AIDS activists. We continue to support the efforts of the Administration to make practical application of surrogate endpoints to improve the rate of AIDS drug approval.

Reform No. 5 — Accelerated Approval.

This reform provides that the "FDA will significantly reduce both the number of clinical studies required prior to approval and the amount of time FDA requires to grant its approval for drugs... used to treat life-threatening, very serious, or severely debilitating conditions and ... drugs to treat any condition, regardless of its severity, when the condition lacks satisfactory alternative therapy." Essentially the reform would do away with any Phase III pre-approval testing requirements in favor of post-marketing studies in appropriate cases and it indicates that the FDA is to rely upon surrogate evidence of effectiveness in these cases.

Consensus Statement:

This reform essentially adopts the accelerated methods used to approve DDI for the treatment of AIDS as the template to be used to accelerate the approval of other drugs to treat conditions as defined above. We believe it only appropriate for us to address in this statement that we support this rationale for accelerated approval in the case of life-threatening conditions as this is the situation faced by our constituency.

Reform No. 6 — U.S. Recognition of Foreign Approvals.

"The Administration and FDA will place high priority on achieving harmonization with other industrialized countries that will enable the U.S. to recognize foreign approvals of drugs, in order to provide American patients with faster access to a broader variety of important therapies."

Argument in Favor of this Reform:

Many critically important treatments for life-threatening conditions have been routinely used in Europe for years before they were approved in the U.S. (AIDS examples include fluconazole, foscarnet, and azithromycin). Clinical trials, "expanded access" programs, and buyers clubs filled part of the gap for those with means. But tragically, many patients died unnecessarily because they lived in the U.S. where these drugs had not yet been approved.

The Council's proposal calls for the development of reciprocity agreements for drug approval based upon agreeing to common standards, common formats for drug applications, common requirements for animal testing, and criteria governing good manufacturing practices and plant inspections. The approach to these reciprocity agreements is not unlike many treaties negotiated with industrialized countries on a wide range of other issues, including national security or defense, and trade. Not to pursue this reform would be a tragic, indefensible squandering of world financial and human resources. It is arrogant to believe that even with these agreements and appropriate safeguards that only if the process takes place on American soil is it good enough.

Reform No. 11 — Staff and Financial Resources.

"To achieve the over-arching goals of reducing the approval times for new drugs, FDA will need to direct its personnel resources to reviewing new drug applications. All new expanded staff will be dedicated to drug approval until these goals are met."

Consensus Statement:

In the last year we have seen the bureaucracy of the FDA suggest to Rep. Henry Waxman that they be given broad new enforcement powers, including the authority for FDA agents to carry guns. We've seen Commissioner Kessler lead the attack against the ever-present danger of orange-juice makers labeling practices. It has become increasingly clear that somehow we needed to get Dr. Kessler to get religion about the right things, to re-evaluate their mission and priorities. This reform is a step in the right direction.

Other Reforms.

Consensus Statement:

The proposals include other, non-controversial and clearly positive suggestions, such as computerizing review of new-drug applications, expanded use of advisory committees, and internal systems of accountability. Other parts of the reform plan address real and critical problems, but also raise legitimate questions and concerns that are outside of the immediate concerns of our organizations. These concerns can and must be addressed by ongoing discussion, debate, and suggestions for improvements in (or alternatives to) the current proposals.

KAISER Patient???

PWA or HIV+???

Problems???

Concerns???

ACT-UP/Golden Gate is sponsoring a community forum for patients of Kaiser to meet and discuss problems and concerns about treatment and research at Kaiser.

DATE--THURSDAY DECEMBER 16TH

TIME--7PM

PLACE--METROPOLITAN

COMMUNITY CHURCH-MCC

150 EUREKA ST

SAN FRANCISCO



415-241-8800

local governments extend social security and medical benefits, including housing, only to those with CDC defined AIDS and in some cases AIDS Related Complex (ARC). It is apparent that the CDC classification for AIDS plays a direct role in the limited funding currently available to women with HIV. Women with life-threatening and severely debilitating illnesses do not have access to funding due to the lack of a formal AIDS diagnosis. This is wrong. Financial and material assistance must be provided to women with HIV disease.

To improve the lives of women with HIV the CDC must produce a comprehensive document on the natural history of HIV disease. We have known about AIDS for ten years, women have been getting AIDS for ten years, yet still very little is known about the manifestations of HIV in women. A natural history of the epidemic in women would provide a basis for treatment research areas to be established.

The CDC has given guidelines to physicians that pregnant women with HIV should be encouraged to have abortions. If a woman is HIV+, yet asymptomatic, the likelihood of her child being HIV+ is less than 25%. If a woman is symptomatic, this vertical infection rate increases. If she is showing positive P24 antigens, an indicator of viral activity, transmission rate increases much higher. Transmission rate from mother to fetus is about 30%. There is no substantial evidence that AIDS progresses more rapidly with pregnancy. Still, women are being encouraged and often coerced to abort pregnancy even though chances are quite good that her child will not be infected with HIV. **Women should be counseled on the risk of HIV infection to her child during pregnancy but she should not be advised, coerced or persuaded in her decision on whether or not to carry a pregnancy to term. Proper education must be made available to women.**

Access to health care treatment and education for women is a broad social problem that is not limited to the AIDS pandemic. When these social problems meet the AIDS pandemic however, the result is fatal. The issues which confront women with HIV infection are broad and varied. There are cultural issues of access to health care which confront women of color, who are the highest population of women currently affected by the AIDS pandemic. There are issues of cultural differences and religious imperatives which hinder access to information to Latina women. There is a profound lack of information on woman to woman transmission of the virus, though there are reported cases of Lesbian transmission. There are social conceptions that women are vectors of disease and there is a tendency to treat a fetus rather than a woman. These issues are no less significant than any other issue. The average life span for white men from the day of AIDS diagnosis to death is 24-36 months. The average life span for women from diagnosis to death is 15 weeks to 6 months. The average life span for a black woman in New York from diagnosis to death is approximately 15 days.

The most important issue facing women with HIV infection, however, is the CDC classifications for AIDS. SAY IT!! WOMEN GET AIDS. Until AIDS in women is recognized and researched more extensively, it is virtually impossible to start to deal with the other issues which confront women with HIV. Women are invisible in the AIDS pandemic. This is wrong. Women get AIDS. Women die from AIDS. Women are being ignored in this pandemic. Effective treatment for women with AIDS cannot be fully established until the CDC acknowledges and reports on how women are being affected by HIV.



ACT UP/GOLDEN GATE **CONTACT: JUDITH COHEN - 863-2562 BRENDA LEIN - 227-4000**

**WORLD AIDS DAY: THE CENTER FOR DISEASE CONTROL'S POLICIES ON
WOMEN WITH HIV INFECTION**

SAY IT!! WOMEN GET AIDS

It is estimated that 1.5 million people in the United States are infected with HIV. Because of the long incubation period of the disease, the number of AIDS cases is expected to rise dramatically over the next few years. It is estimated that in 1992, 40% of newly reported cases of AIDS will be in women. In New York, AIDS is the leading cause of death for women of childbearing age.

Epidemiologists have been charting the demographic shift of the epidemic toward women, Hispanics and blacks for several years. Women are among the fastest growing groups of newly infected persons with HIV in the United States. Women are also the most misdiagnosed, underdiagnosed and underserved population in the AIDS pandemic.

The AIDS Coalition To Unleash Power, ACT UP/Golden Gate's DEMANDS to the CDC to improve the lives of women with HIV are:

- **That the Center for Disease Control (CDC) re-define AIDS to include diseases which are HIV related and are specific to women**
- **That the CDC publish a comprehensive document on the natural history of HIV in women**
- **That the CDC revoke guidelines to physicians recommending abortion for HIV+ women and instead establish a standard of care which counsels women on transmission risk but does not advise or coerce abortion**

Of the issues confronting women with HIV, the most serious is the CDC's classifications for AIDS. The Center for Disease Control (CDC) is a clearinghouse of information for diseases and epidemics. It tracks the epidemiology of diseases, manifestation and demographics and defines diseases based on this information. A case of AIDS is defined as an illness characterized by one or more opportunistic infections depending upon the status of laboratory evidence of HIV infection. The definition of AIDS that the CDC recognizes does not include life-threatening and debilitating illnesses which are specific to women. Pelvic Inflammatory Disease (PID), chronic Candidiasis, Chlamydia and Human Papillomavirus (HPV) are a few of the manifestations of HIV which are specific to women. Many HIV+ women die of complications from these opportunistic infections without ever receiving an AIDS diagnosis, as these illnesses are not classified as AIDS defining. Because the CDC does not recognize women specific opportunistic infections, women are not accurately represented in national statistics on AIDS. If a woman dies of PID or HPV, even though she is HIV positive, her death is not registered as an AIDS death.

50% of women infected with the AIDS virus in San Francisco have been HOMELESS at some point during their HIV+ status. An AIDS diagnosis is important to make one eligible for social security benefits and other funding which is available for people with life-threatening illnesses. A diagnosis of PID does not make a women eligible even for disability insurance, though it is often severe and requires long hospitalizations and frequent surgery when manifested in women with HIV infection. Federal, State and