ACT UP SAN FRANCISCO

AIDS COALITION TO UNLEASH POWER
2300 Market Street #68 San Francisco, CA 94114

Terry Sutton

We Will Never Forget

ACT UP’s Terry Sutton died on April 11. Terry was a central figure in ACT UP, one of the founders of the original AIDS Action Pledge, and a person known for his ability to push us with his politics and crack us up with his goofiness. The following is excerpted from a speech given at Terry’s memorial march and rally.

By Michelle Roland

Terry had a sign on his bedroom wall that said “I am not reconciled to dying an unjust death.”
Terry died as he lived - fighting every inch of the way. His death was painful, gruesome, and a struggle. There was nothing peaceful, reassuring or comforting about it. Terry was not reconciled to die an unjust, pre-mature death. To any one who spent time with him in the hospital, that was clear.

I am here today, as are most of you, because I am not reconciled to Terry’s having died (continued on page 9)

'A Brave, Crazy Soul'

by Marty Blecman

I had a great gift to be able to live with Terry Sutton for the last year. I don’t think anyone will ever fill the huge void he has left, but surely his spirit will live on with us forever.

My fondest memories are watching Terry spoil my dog Max silly. He had this bond with Max that was healing, grounding and so joyful that somehow Max got Terry through some very tough times. Out of nowhere, Terry would start squawking like a wild big bird and just hop around and freak out the dog, not to mention crack us up.

He got hooked on Star Trek, War of the Worlds, speaking in alien tongue, “Magwa” is alien

for Mama, loved his fish tanks, plants, Greek music, had a passion for India, of course Gandhi, and a few porno tapes.

Sometimes he would come home and just fall apart crying in my arms. As tough as the Warrior portrayed himself, he was basically this dear little boy who was just as terrified and human as everybody else. I’ve never met a more compassionate, intelligent, brave, crazy soul who taught a lot of us a great deal about love, humor, commitment, life, death and the human condition.

MAGWAS, “Bark, bark, Fight back, Fight AIDS.”
Our Goals and Demands

ACT UP (the AIDS Coalition to Unleash Power) is a nonpartisan group of diverse individuals united in anger and hope. We are committed to direct action to end the AIDS crisis. We demand massive governmental funding for research, health care, education, anonymous testing, and treatment. The research for treatments, vaccines, and cures should be centrally coordinated and publicly accountable to the communities most affected. We demand free nationalized health care guaranteeing equal access, regardless of ability to pay. We demand a federally-funded sex positive education program to promote safer sex. We demand that information on needle hygiene be made available to all needle users. We further demand that addiction treatment/recovery programs be expanded and available to all regardless of ability to pay. We further demand that these programs be instituted in a culturally sensitive international program.

ACT UP/San Francisco grew out of the AIDS Action Pledge, implemented in 1987 to respond to the deplorable government and private sector response to this crisis. We’re part of a growing worldwide movement, coordinated nationally through ACT NOW (AIDS Coalition to Network, Organize, and Win). ACT NOW can be reached at 2300 Market Street, Suite 87, San Francisco, CA 94114, (415) 861-7505.

Correction

We apologize to Rick Gerharter for leaving off his photo credits in the March-April newsletter. All of the photos were by Rick.

How To Get This Newsletter

This newsletter costs approximately $.50 per issue. We understand that not everyone who needs/wants this newsletter can afford it. But if you can, please send us the money to cover you issues and that of someone who can’t afford it. And if you want to make a contribution, please do so.

Also, if you prefer to not receive the newsletter, please return the coupon with that information.

ACT UP/SF Events line 563-0724

ACT UP
SAN FRANCISCO
AIDS COALITION TO UNLEASH POWER
VOLUME 1 NUMBER 2 MARCH 1989

The ACT UP/SF newsletter is published by the Newsletter Committee of ACT UP/SF. At the moment, the group consists of Buckwheat, Ed, Eric, Richard, Sean, Mic, and Mike. Articles appearing here do not necessarily represent the viewpoints of all those involved with ACT UP/SF.

Letters and material appropriate for publication may be submitted to our NEW ADDRESS:

ACT UP/SF
Newsletter Committee
2300 Market Street, Suite 68
San Francisco, CA 94114

Send a photocopy, not the original.
For additional information on ACT UP/SF events call the Hot Line at 563-0724.

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Hot Briefs

Compiled by Mic Sweney & Richard Uhsmann

New York, NY, March 28. At the largest action in ACT UP/NY history, over 3000 protesters blocked Manhattan streets and disrupted N.Y. City Hall. Waves of affinity groups blocked both the entrance and exit of the Brooklyn Bridge to dramatize the demand that the city respond more quickly and effectively to the epidemic. Before the end of the 2 hour siege, 190 demonstrators were arrested amid instances of excessive police force. N.Y. police later admitted that arrestees were illegally questioned whether they were homosexual and that 30 women were illegally strip searched. There are now law suits pending as a result of the stripsearches.

Oakland, CA, April 1. A crowd of 400 came together under the auspices of “People of Color Mobilizing Against AIDS” in Oakland to bring their message to the National Conference of Black Mayors. “Face the facts/it’s not too late/ AIDS does not discriminate!” was the rallying cry.

Minneapolis, MN April 2-7. Hans Paul Verhoef, a Dutch AIDS activist was detained and held at a maximum security penitentiary on April 2 by Minneapolis Immigration and Naturalization Service officials (INS) while on route to the eleventh annual Lesbian and Gay Health Conference in S.F. After protests in the US and Europe (see Zaps and Actions, Page 8), the INS released Verhoef.

Columbia, SC In response to recently enacted legislation, ACT UP/Atlanta organized a noisy protest outside South Carolina’s State Capitol. A group of 125 individuals, 25 of them from South Carolina, demonstrated for 2 hours. Following the demonstration, 41 people were arrested for blocking an intersection. Of those arrested, ACT UP/NY made up 27 of them. South Carolina’s AIDS law, passed by the General Assembly last year, prohibits confidential or anonymous HIV antibody testing, establishes quarantine provisions for certain HIV antibody positive individuals, and extends prison sentences for positive testing inmates. The law also requires state disclosure of HIV antibody status for persons suspected of carrying or transmitting the virus.

Raleigh, NC April 25. 3 AIDS activists seized an office at the Burroughs-Welcome U.S. headquarters. The bold trio barricaded themselves inside, demanding that the profit making company lower the price of AZT. In the end, company officials broke down a wall to get to the protesters and had them arrested.

Couer d’Alene, ID, April 22. Representatives of ACT UP/SF, ACT UP/Portland, and ACT UP/Seattle joined 1200 - 2000 other civil rights activists in Couer d’Alene, Idaho, the “headquarters” of Tom Metzger’s Aryan Nations group, to protest a national gathering of around 50 Nazi skinheads. It was estimated that around 25% of those protesting the Nazi gathering were lesbians and gay men. This was the first civil right demonstration in Idaho.

Austin, TX, May. 20,000 people marched on the Texas state capital demanding decriminalization of sodomy, enactment of anti-hate laws relevant to lesbians and gays, and full access to health care. ACT UP/AUSTIN held a treatment issues tribunal and wrapped the capital in red tape.
by Patricia Case with Sean McShee

Ever since the (unsanctioned) Prevention Point needle exchange project came out in the press, there’s been considerable support for the program on the part of city and state officials. Public Health Commission hearings are being held May 16th, but it is clear to me that the question is not if a sanctioned needle exchange will happen here but what it will look like, who is going to run it, and how long it will take. Since the discussions now going at the Department of Public Health and the Mayor’s Office will shape this program public demands will influence the course of the discussion.

Intravenous drug users (IVDUs) make up the second largest group of HIV infected individuals in the United States. According to the CDC

**Needle exchange is a simple and matter-of-fact measure that should have been instituted by the Department of Health years ago. Not doing so has endangered many lives.**

(January 16, 1989), 16,492 AIDS cases (20% of the total) have IVDU as a primary risk. An additional 5,944 (7% of the total) have both IVDU and male-to-male sexual contact as a risk. Those IVDUs who have female-to-female sexual contact as a risk remains, of course, unknown. 80% of the IVDU cases, and 40% of the male-to-male sexual contact/IVDU cases, have occurred among people of color. The rate of HIV infection among IVDUs is 57% in New York and 15%-20% in San Francisco.

The mode of HIV infection is through blood-to-blood contact through the sharing of injection paraphernalia - syringes, cookers and bags (used to prepare drugs for injection), and cottons (used to filter the drugs before injection). The bleach campaign coupled with street-based education started by MidCity Consortium to Combat AIDS (MCCA) in 1986 appears to have had considerable success in teaching IVDUs needle hygiene. While rates of infection in other cities have climbed among IVDUs, in San Francisco rates have stabilized since 1986 at between 15-20% overall. Particularly in those neighborhoods where MCCA’s health workers operate.

However, lack of access to clean works prevents many IVDUs from protecting their health. Needle exchange is a simple and matter-of-fact measure that should have been instituted by the Department of Public Health years ago. Not doing so has endangered many lives. In New York while needle exchange was debated or the last two years, the rate of infection soared to 57%. We can’t let that happen here.

The sanctioned exchange models available for consideration are:

**The New York Model** This model was developed in the face of very serious public criticism of needle exchange. Only IVDUs on a waiting list for drug treatment are eligible. The program is housed in the Department of Public Health downtown, a long 1 or 2 bus rides for most IVDUs. Once there they are asked for their names and have their pictures taken for photo ID. The client is then interviewed with a risk questionnaire and is given 1 syringe. This intake procedure takes about an hour and a half. While New York has hundreds of thousands of IVDUs, this pilot program has only 200 slots. Less than 100 have enrolled.

**The Tacoma Model** The Tacoma, Washington needle exchange started as a private action but was funded by the Public Health Department. It is street-based, in a neighborhood where IVDUs hang out. The health worker sets up a small table with a biohazardous waste bucket on it, in which IVDUs drop their needles. They can exchange on a one-to-one basis up to 10 syringes, and obtain cotton, cookers, bleach, condoms, and information about treatment programs. There are no requirements to enroll and no questions asked. Since this is a sanctioned program the Department of Public Health also provides a nurse who conducts a clinic-in-the-street next to the needle exchange, doing
assessments of abscesses and giving medical referrals, possibly the only medical attention these IVDUs have.

The Boulder, Colorado Model In this model existing public health outreach workers

There has been a suggestion that the needle exchange program would be limited to one neighborhood... Another neighborhood would be the 'control.'

simply added syringes to their repertoire of condoms, bleach and other prevention materials. The District Attorney declined to press for enforcement of syringe laws because he felt that the law was not enforceable in an epidemic. Because of the small size of Boulder a street based program would threaten IVDUs anonymity. This is more of a home-based program and in the context of AIDS prevention education, IVDUs can exchange syringes with outreach workers.

Most unsanctioned needle exchange programs lean to the street based model, because it is cheap, effective and doesn’t jeopardize existing agencies. Currently, unsanctioned needle exchange and distribution programs are operating in Seattle, Oakland, Boston, New Haven, New York City, and Providence. More are being planned for Chicago, Phoenix and other cities.

In order to adopt a model that will work - that is to reduce needle transmission of HIV- a needle exchange program should be:

Street-based Common sense indicates that the best way to get someone to change is to ask them to make only a small change. IVDUs don’t have to do anything different at a street based needle exchange to get a clean needle except bring an old syringe instead of the $3.00 that a needle costs on the streets of San Francisco. It’s an accessible, low-key AIDS intervention program that operates in the natural context of IVDUs - the street.

Anonymous Whether or not clean needles are sanctioned, the injection of drugs remains a crime, and IVDUs are, by definition, thought of as unapprehended criminals. Having a needle exchange program that is anonymous increases accessibility, and the possibility of success.

City-wide Public health officials require an evaluation of intervention programs to see if the program is effective. However, there has been a suggestion that the needle exchange program would be limited to one neighborhood in San Francisco. Another neighborhood would be the “control”. However, when the outcome variable is the rate of infection of a deadly virus, to limit a potentially lifesaving program to one neighborhood is extremely unethical. It is also scientifically unsound, as IVDUs are not lab animals in cages. IVDUs can get on the bus with everybody else.

Treatment linked not treatment centered Many of the IVDUs in San Francisco never come into contact with a treatment program. Either they don’t want treatment, or there is not appropriate treatment for their particular drug of choice, or they cannot afford it. Basing an exchange program in the treatment clinics would limit access to clean syringes.

However, if using needles puts someone at risk for HIV, one AIDS prevention strategy is to go into drug treatment. The waiting lists, cutbacks in services, and lack of amphetamine/cocaine related drug treatment is very serious. In conjunction with a needle exchange program, expanded drug treatment must be instituted and funded so that all who want it, can get appropriate treatment on demand. Treatment vouchers are a solution. A needle exchange client who asked for a voucher could have a selection of appropriate programs, and present the voucher the next day for immediate treatment.

These are just some thoughts about how a sanctioned needle exchange could be set up. Prevention Point will continue to operate the San Francisco needle exchange in the meantime.
May

15 Artists Against AIDS, ‘ACT UP/SF at ATA’, opens the week long art benefit series with members of ACT UP/SF reading, being theatrical and performing. See box for details.

16 Hearings on Needle Exchange, SF Dept. of Public Health, 101 Grove, 3rd Floor, 2pm.


18 ACT UP/SF general meeting, 7:30, 150 Eureka St.


BWMT Rap Group, ‘Crime in the Gay Community’ with Huda Jadallah, a rep from CUAV, 1350 Waller (Ashbury/Masonic), 7:30, Donation.

19 Artists Against AIDS, ‘Six Men; Six Views,’ Dance, Performance Art, Theater, See box for details.

10th Anniversary ‘Dan White Night’ March and celebration of lesbian/gay life, 8pm, Harvey Milk Plaza (Castro & Market), drag encouraged. For info, call 995-4735.

20 Art Against AIDS, ‘Performers Against AIDS’, Pat Califa and Aaron Shurin (among others). See box for details.

21 Talk Story a Musical Benefit for Asian Health Services, Theater Artaud. $25. Call 465-3271 for info.

25 ACT UP Educational, ‘What it Means to be PIS’D (a Person with an Immune System Disorder)’ put on by the PIS’D caucus, 7:30, 150 Eureka St, General Meeting follows.

Dance benefit for Asian/Pacific Lesbian Network Retreat, Women only 9pm to 2am, 224th St. (between Mission and Market). Sliding Scale $6-12.

26 20th Anniversary Reunion Gay Liberation Fronts New York, Berkeley, and DC, 7:30 pm , Women’s Building, 3543 18th St. ($5), Call 775-6143.

California Men’s Gathering, (for information call 928-1834).

27 ‘Safe Sex Tropical Nights with Las Chikas’ La India Bonita, 3089 16th St. (at Valencia). 10:45. Presented by the Latino AIDS Project.

Carnaval, Harrison St. (between 16 and 21st Sts.) from 11 am to 6pm. Bands. A benefit Conga line (part of ‘IN CONCERT AGAINST AIDS’). Call 826-1401 for info re the benefit Conga line.

28 AIDS Candlelight Memorial March, 8:15 pm, Harvey Milk Plaza (Castro & Market) to Civic Center, for info call 863-4676.

Carnaval Parade through the Mission with floats and bands. Call 826-1401 for info.

31 Meeting to plan for the national Lesbian gathering at Mama Bears, 6536 Telegraph. Women only. Call 621-4472

June

1 ACT UP/SF, general meeting, selection of one-half of the Coordinating Committee, 150 Eureka St.

8 ACT UP/SF, general meeting, 7:30 pm 150 Eureka St.

Live broadcast from the International AIDS Conference in Montreal. Call 1-800-262-0834 for details (like what station?).
Zaps & Actions

by Eric Slade

Sacramento, March 13.- About 20 ACT UP/SF people descended on Sacramento, Wednesday, March 13 for a day of zaps and protests against the Governor’s homophobic and PWA-hostile actions.

We joined with members of ACT UP/Sacramento for chanting and picketing on the Capitol plaza and (after police kicked us off) on the sidewalk. After a brief visit to the Governor’s office we moved on for an extended visit and “dialogue” with members of Senator Doolittle’s staff. (Doolittle is the California legislative equivalent of Jesse Helms or William Dannenmeyer.) The day was successful

Calendar, continued from previous page

15 ACT UP/SF, general meeting, 7:30 pm, 150 Eureka St.

16-24 Lesbian-Gay Film Festival at the Castro, call 861-1404 for info.

22 ACT UP/SF, educational ‘Lesbian-Gay Liberation/AIDS Politics?!” 7:30 pm, 150 Eureka St, general meeting follows. Deadline for stories July-August issue.

25 LESBIAN GAY FREEDOM DAY AND MARCH, call events line 563-0724, for where the ACT UP contingent will meet.

29 ACT UP/SF, social, 7:30 pm, 150 Eureka St. Deadline for calendar items July-August issue

July

6 ACT UP/SF, general meeting, selection of one-half of the Coordinating Committee, 150 Eureka St.

13 ACT UP/SF, general meeting, selection of one-half of the Coordinating Committee 7:30 pm, 150 Eureka St.

15 July-August newsletter out.

Ongoing Events

ARTISTS AGAINST AIDS, all events, 922 Valencia, 8pm, for info call 824-3890.

May 21-27, ‘IN CONCERT AGAINST AIDS’ mega-benefits by Bill Graham et al for AIDS education and support organizations. Call 762-BASS for information (or check any local paper).

For Information regarding defense of reproductive rights against Operation Rescue call BACAOR 824-8562. Attacks are coming more often, so stay informed.

For information regarding an upcoming protest against circumcision “The Victims Speak”, call 285-0260. Not only is this operation unnecessary, but is almost always performed without the subject’s knowledge or consent.

Wear a pink ribbon to show support (and publicize) the demands of Stuart McDonald. Demand anti-discrimination legislation to protect lesbians and gays and people who are HIV positive.
Zaps, continued from previous page
in raising consciousness and increasing visibility in Sacramento about AIDS.

Terry Sutton March, April 24 - Around 200-250 people gathered the evening of April 24 for a march and rally in memory of ACT UP’s Terry Sutton (see related stories in this issue). The crowd gathered at Harvey Milk Plaza for speeches and music that touched on many aspects of Terry’s life, his work, and the work still ahead for all of us. We chanted and carried signs and photos of Terry. The crowd then took to the streets, marching through the Castro, to Terry’s house on Noe St. and then on to Ralph K. Davies Hospital, just a block away.

Speakers at the hospital pointed out that Terry could have simply “hopped out of his bed and into a bed at Davies” had he been accepted into the Foscarnet drug protocol, a drug trial that could possibly have saved his life. Terry was denied access to the trial.

The march returned to the Castro for a rousing closing circle that blocked traffic at Market and Castro for around 30 minutes. As the circle dispersed and the event was near its end, police formed a line and began marching down Castro street to push protestors onto the sidewalk. The crowd began chanting “Cops out of the Castro,” and, eventually, the cops regrouped, turned around, and marched back from where they came, persued by triumphant protestors. An empowering end to a march and rally that paid tribute to Terry in words, action, and spirit.

AZT Rally, March 31 When word reached ACT UP/SF that federal funds for AZT would not be renewed, thanks to yet another wretched parliamentary maneuver by Jesse Helms, we quickly put together a rally and march. About 125 people assembled on short notice at Harvey Milk Plaza to march to the ARC/AIDS Vigil at the Old Federal Building. Last minute congressional maneuvering eventually restored, for now, funds for AZT.

The Lesbian & Gay Health Conference, April 5-9. The 13th Annual Lesbian & Gay Health Conference held here provided plenty of opportunity for ACT UP events. When Dutch AIDS educator Hans Paul Verhoef was jailed by Immigration officials on his way to the conference local activists, including those from ACT UP/SF, responded quickly with a demonstration and civil disobedience at the Old Federal Building. (Verhoef was later released and attended the conference. Immigration laws which caused his jailing remain unchanged). (See Hot Briefs, Page 3)

ACT UP/SF and ACT UP/NY jointly put together two caucuses during the Health Conference. The meetings brought together activists and potential activists from all over the country. Participants shared experiences and discussed strategies. ACT UP/SF and ACT UP/NY also hosted a table throughout the conference, handing out information, selling T-shirts, and doing that 80s thing, networking.

People from ACT UP/SF also took part in the following events: the Pro-Choice March (April 2), Peace in El Salvador March and Direct Action (March 18 and 20), People of Color Mobilizing Against AIDS March (April 1), Stop Operation Rescue (April 29), and the We Won’t Take Four More Years march and rally (April 29).

Check calendar for upcoming events.
an unjust death, not am I reconciled to the 50,000+ unjust deaths in the US before him or the many thousands that are sure to follow him.

I am here to speak the truth about Terry’s death and to share the truths about our government, the medical and research communities, our society, and even our own lesbian and gay community that Terry worked so hard to educate us about.

Terry was very clear about what he needed in order to survive. Terry, like all HIV infected people, needed drugs and treatments to fight HIV and the opportunistic infections and cancers that plagued him. Because our government has been so slow and so inadequate in its response to the AIDS epidemic, the vast majority of promising treatments are not approved, and therefore not available for use by people with HIV infection and their physicians. Too many promising treatments are not even yet in clinical trials due to drug company greed, bureaucratic red tape, inadequate federal funding and a total lack of coordination of pre-clinical drug testing and clinical trials.

Ultimately, the only hope that people with HIV infection have is access to experimental treatments. AZT, by itself, won’t keep us alive.

Yet experimental treatments are only available to a very few people fortunate enough to qualify for the stringent requirements of most protocols, and lucky enough to live near one of the medical facilities where the protocol is available.

Experimental treatments, once they have been shown to be reasonably safe, need to be made available to all people with HIV infection who want to try them - no matter where they live, no matter how much money they have, no matter, even, if the drug has not yet been proven to be effective for the purpose that it is being taken.

When there are no effective choices, people must have the right to choose to try unproven treatments. It’s a simple as that.

Terry was denied that right. Terry had CMV retinitis, a common opportunistic infection in AIDS. Without treatment, CMV retinitis rapidly causes blindness. The standard treatment for CMV is a drug called DHPG or gancyclovir. What we know about DHPG is that it works - it prevents blindness - for a while - commonly about a year. What we also know about DHPG is that ultimately everyone who takes the drug will fail on it. The drug will either become ineffective at a tolerable dose and the person will go blind, or the drug itself will cause such severe depletion of the bone marrow that the person will become extremely susceptible to infection and, like Terry, will die from that infection. DHPG is a dead-end drug.

Terry found out about six months before he died that there is an alternative - a drug called Foscarinet. Because Foscarinet is not toxic to bone marrow, you can take AZT with it. Unlike treating CMV with DHPG, Foscarinet would have allowed Terry to treat both the CMV which was making him go blind and the HIV which was destroying his immune system.

Foscarinet is still in extremely limited clinical trials. Until Terry started causing trouble, there was only one place to get it if you’d already been on DHPG - in Houston. But you have to get yourself there and pay for the hospitalization. Because of Terry’s relentless efforts, a salvage protocol was started at Davies for people who have failed DHPG. But there are still problems - Terry couldn’t have Foscarinet simply because he wanted it, or because he wanted to take AZT and try to deal with his HIV, or even because he knew that DHPG would ultimately fail him.

And by the time he was eligible for Foscarinet, by the time he had "failed" DHPG, his white blood cell count was so low that he slipped into sepsis and died.

The system failed Terry Sutton. Astra, the drug company that won’t release Foscarinet on compassionate use failed Terry Sutton and is failing hundreds and thousands of people in his position every day. The FDA, with its regulations insisting on proof of efficacy before release failed Terry Sutton and thousands like him. Congress, in refusing to legislate humane, affordable, accessible experimental drug access failed Terry Sutton. And we also failed Terry - we did not yell loud and hard enough and long enough to shame those people into releasing Foscarinet.

Foscarinet is only one example. There are
Uncompassionate Treatment

by Mic Sweney

On April 20, 1989 Adria Laboratories discontinued compassionate use of Rifabutin for the treatment of MAI (Mycobacterial infection). Dr. Bianchine, Protocol Manager for the drug experiment (phone number [614] 764-8205), stated that too many people were receiving this drug under compassionate use. The alternative to Rifabutin is treatment with Rifampin which has been known to produce many side effects such as headaches, fever, stomach cramping and extreme fatigue.

Activist and Project Inform worker David Glassberg discovered compassionate use was discontinued immediately after his own MAI diagnosis. Glassberg talked directly to an Adria laboratories' Dr. Bianchine who told him that the high cost of the drug's compassionate use was the reason for discontinuation. When he phoned later Dr. Bianchine told Glassberg he had made been mistaken in citing costs as a problem; he meant to say the company was not getting the research information it needed.

MAI is a bacteria related to the tuberculosis bacteria, but is not airborne. Most PWA's are exposed to this bacteria while eating fruits or vegetables which are uncooked or improperly washed. MAI causes persistent and sometimes severe diarrhea and is difficult to treat.

If you would like to discuss compassionate use of Rifabutin(ansamycin) write or call: Adria Laboratories, P.O. Box 16529, Columbus Ohio 43216-6529.

A New, Improved ACT UP/SF

by Sean McShee

ACT UP/SF has set priorities and changed its internal structure. This new structure seeks to sharpen our focus, to provide continuity from one action to the next, to prevent burnout and to consolidate all action-related tasks.

After brainstorming what people wanted to work on, three broad areas of focus emerged: 1. Treatment Issues, 2.) Local (San Francisco) Issues, and 3.) State/Federal Issues. These three broad areas of focus have become three committees which integrate the responsibilities of Action, Outreach and Education. As these three new committees have their former responsibilities the Action, Education and Outreach Committee no longer exist.

Together with the other committees and caucuses (see box this page) reps from these committees form the Coordinating Committee.

We hope to establish working groups that will meet informally and infrequently to share skills and knowledge.

Committees that have already chosen a rep have an ‘(r)’ after their name and number. Those with a ‘(c)’ are contact people.

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Never Forget, from previous page

many, many more.

This truth is extremely scary.
CMV is a killer. 90% of the gay population is believed to have been exposed to CMV. As people with AIDS live longer because of PCP prophylaxis, more and more are being blinded by CMV. And an untold number are dying from the horrendous effects of systemic CMV infection. When we talk about Foscarinon, when we ask for Foscarinon, we are literally asking for the possibility of saving our sight and our lives.

Maybe Terry wouldn’t have lived long enough on Foscarinon to be around when HIV truly becomes a manageable chronic infection. But who among us believes that we ever had the right to take that possibility away from him?
ACT UP/SF stays busy day and night pointing out what's wrong and demanding what's right. We're loud, contentious and effective.

We went to Burroughs-Wellcome to expose AZT price-gouging, We joined with nationwide ACT UPs in shutting down the FDA to demand an end to deadly drug policies, We're vigilant in demanding access to foscarnet and other needed treatment drugs. And each week we take on new challenges....

We need money to keep our efforts going. No one in ACT UP gets paid, we have no office and no staff. Every dollar we receive goes directly into fighting the AIDS epidemic through meetings, demonstrations, and actions.

Give what you can, and help keep us Acting Up

Here's some money, keep up the good work!

_ $20 _ $30 _ $50 _ $100 (Donations of $100 or more receive the exclusive ACT UP/SF "Silence = Death, Action = Life" T-shirt. Indicate S, M, L, XL.)

Name
Address
City____________ State____________ Zip____________

[] Put me on the Newsletter mailing list  [] Put me on the phone tree for upcoming actions

Mail to:
ACT UP/SF 2300 Market Street
Suite 68 San Francisco, CA 94114
West Coast ACT UPs Shut Portland FDA

by Mic Sweeney

Portland, OR, Feb. 27- Activists from Portland, San Francisco, Seattle, Vancouver and Eugene converged on the office of the US Food and Drug Administration in downtown Portland to protest FDA drug policies. About 100 demonstrators marched and picketed in front of the Federal Building shouting, "No more delays, arrest the FDA" and "Bush and Quayle belong in jail". Authorities arrested 12 AIDS activists during the demonstration called by ACT UP/Portland.

The doors of the federal building were splattered with red paint and by the end of the morning the entire outside was decorated with a mass of stickers, signs and colored yarn. About 25 people went inside the building chanting and yelling and eleven were arrested and charged with creating a disturbance. Everyone taken into custody was cited and released on misdemeanor charges and must reappear in two weeks time.

Michael Petrelis of Portland who was arrested in the civil disobedience was quoted as saying, "until there is a cure for AIDS, we are keeping the pressure up." ACT UP demands that the agency provide immediate, free access to any promising drugs, that the agency stop the use of placebos, that patients participating in drug trials be allowed concurrent use of other life saving treatment, and that the agency end discriminatory inclusion criteria.

Zaps and Actions

by Eric Slade

Here’s what’s been happening.

Counter Inaugural On Jan. 20, while DC was spending millions on a gaudy inaugural carnival, ACT UP/SF was busy hosting our own (much cheaper and much more gaudy) counter-inaugural demonstration including a cardboard limo, secret service agents, and a mock swearing in.

Around 7:30 am 6 ACT UP/SF members arrived at the Pacific Stock Exchange seeking a tour. When there request was denied, they chained themselves to the front doors, stopping any traffic through the entrance. Eventually all 6 were arrested and charged with refusing to leave private property and

"Babs, Skippy, and George" prepare to take the oath of office at ACT UP's Jan. 1 counter-inaugural.

sentenced to 10 hours of community service.

Meanwhile our counter-inaugural procession began its march from the ARC/AIDS vigil to the Pacific Stock Exchange. We stopped at Carl's Jr.
Zaps, Continued from page 1
(where last winter a PWA died on the street after being thrown out of the restaurant) for a die-in commemorating PWAs who have died homeless.

After arriving at the Stock Exchange, there were several rousing speakers, picketing, and a closing circle which blocked traffic briefly, causing the police some momentary job related stress, but there were no additional arrests.

Fauci Demonstration Dr. Anthony Fauci, Director of the National Institute of Allergies and Infectious Diseases (NIAID) one of the main Federal Agencies responsible for what passes for AIDS policy was in San Francisco on Jan. 17 to receive an award at the SF Hilton for his contribution to public understanding of science.

Several ACT UPers interrupted Fauci’s award ceremony by reading a statement accusing him of clumsiness in initiating programs and silently accepting budget cuts. Fauci was told, “it is time for you to get angry like the rest of us. We need you to undertake a serious fight against AIDS with staffing and funding adequate to the task.” In his speech afterwards Fauci acknowledged the legitimacy of the protestors actions.

Foscarnet 10 people demonstrated at the San Francisco General Hospital pharmacy on Feb. 13, demanding access to foscarnet. The drug (a promising treatment for CMV retinitis) is currently on the shelves of the SF General pharmacy, but is available to only 29 people in San Francisco. (See treatment issue article this issue, page 5.)

Protesters formed a line at one of the pharmacy and told the pharmacist, “I’m a person with AIDS and I would like foscarnet so I can save my sight.” After a brief dialogue the group was told they couldn’t have the drug. The group then sat down to wait for a change in policy or arrest.

After several hours of protest and consciousness raising, demonstrators declared the event a success and left the area.

Check the Calendar on page 7 for upcoming events.

ACT UP SAN FRANCISCO AIDS COALITION TO UNLEASH POWER VOLUME 1 NUMBER 2 MARCH 1989

The ACT UP/SF newsletter is published by the Newsletter Working Group of the Education Committee of ACT UP/SF. At the moment, the group consists of Buckwheat, Ed, Eric, Richard and Sean. Articles appearing here do not necessarily represent the viewpoints of all those involved with ACT UP/SF.

Letters and material appropriate for publication may be submitted to:

ACT UP/SF Education Committee P.O. Box 460693 San Francisco, CA 94114

Send a photocopy, not the original. For additional information on ACT UP/SF events call the Hot Line at 563-0724.

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HOT STUFF

by Sean McShee and Mic Sweeney

San Francisco, Jan. 31. The group Stop AIDS Now or Else blocked the Golden Gate Bridge during the a.m. rush hour for 40 minutes. Some stretched a large banner across the bridge, some sat down in the lanes of traffic, while others passed out leaflets. Police arrested 26. This action generated massive publicity and public debate around both AIDS issues and the tactics of the action.

San Francisco, CA. In a report in the Tenderloin Times, the San Francisco Coroner listed the causes of death for the 103 homeless who died on city streets during 1988. At least 2 died from AIDS. 9 died after being released from hospitals while still ill. Since anyone who died with an ID bearing an address, or who died while hospitalized for a long period of time was not listed as homeless, the actual figures for both AIDS dead and homeless dead may be much higher.

Washington DC The Feb. Edition of the Journal of the American Public Health Association rated from 0 to 100 various members of Congress on their voting record on public health issues -for 1988 Cranston scored 78%, Wilson 67%, Pelosi scored 100%, Dellums 94% and Boxer 89%. That guardian of the public health Dannenmeyer was one of the two California reps to score a perfect 0% (the other was Shumway).

Denver, CO. When Governor Romer failed to mention AIDS in his state of the state address of Jan. 12, protestors, many of them ACT-UPers, disrupted the his speech, unfurling an "ACTION EQUALS LIFE" banner while shouting, "What about AIDS?" No arrests were made. Later that day a state budget committee voted unanimously in favor of a bill providing long term care services for AIDS related health conditions. On Jan. 17, Gov. Romer issued an executive order prohibiting discrimination against individuals with HIV infection.

San Francisco, Jan. 12: Stuart McDonald, a PWARC, began a hunger strike against Dukemejian's discriminatory policies against lesbians and gays and HIV-infected people. Dukemejian has twice vetoed anti-discrimination legislation. Doctors have stated that the hunger strike will cause his ARC diagnosis to escalate to AIDS. As of press time he was approaching his 50th day of the fast.

San Antonio, TX, Jan. 19. Army Private John Bribois has sued the Army at Fort Hood, TX, charging that the Fort Hood brass have established a de-facto quarantine ward of HIV positive GIs at Fort Hood. San Antonio AIDS activist Papa Bear has collected statements from witnesses to Lt. Gen. Saint publically joking that he operated "the largest leper colony in the US."

Several new ACT-UPs have formed in the following areas:

Syracuse, NY The group will be protesting discrimination against local people with HIV related illness.

Sonoma County, CA Sonoma activists are organizing a protest against discrimination in Sonoma County against PWAs; an action is planned for March. Call 865-2159 for more information.

SF State University Some students are working to educate the greater university community around the political and social issues concerning AIDS. For more information call Rick 552-1775.
Lesbians and HIV: The Numbers
by Patricia Case

What we don’t know about lesbians and HIV is so frustrating. What is the rate of HIV infection among women with a lesbian identity? Nobody knows. There are three reported cases of sexual transmission between women, but what is the real risk of sexual transmission between women? Nobody knows. Is it a rare event or not? Nobody knows. The Center for Disease Control does not collect data on sexual transmission of HIV between women in AIDS reporting. Is it happening? Nobody knows.

In the big seroprevalence studies, where data on sexual identity and behavior is available, sample sizes are too small to be “statistically significant” and consequently go unreported. Donna Minkowitz of the Village Voice reports Dr. Charles Schable of the CDC feels that the CDC does not investigate sexual risk because “lesbians don’t have much sex”. A category of behavior, female-to-female sexual transmission, is simply dismissed as a possibility although the theoretical basis for transmission to occur between women has been established. Lesbians have become a reverse risk group, with scientists refusing to investigate because they have an intuition that female-to-female transmission isn’t happening. Is homophobia about a sexual identity preventing investigation into sexual behaviors that women of all sexual orientations (and men) may engage in? What’s going on here? Nobody knows?

This is what we do know. There are (as of May 1988) 101 cases of AIDS among lesbian and bisexual women, with IV drug use being the primary risk behavior. Dr. Peter Drotman of the CDC presented a poster titled “AIDS and lesbians: IV drug use is the risk” at the Fourth International Conference on AIDS in Sweden that included the following table. This information comes from a case review of CDC AIDS case reports. Women who had sex with both men and women were categorized as bisexual and women who had sex with only women were categorized as lesbians. Do call Dr. Drotman for an update on the numbers if more current information is needed.

Among the 50 Lesbian-identified women, 38 (76%) had the risk behavior of IV drug use, 5 (10%) had had transfusion, 4 (6%) were immigrants and 3 (6%) had no known risk behavior. Among the 51 bi-sexual identified women, 44 (86%) had the risk behavior of IV drug use, 1 (2%) had had transfusions, 5 (10%) had heterosexual contact with an HIV+ male, and 1 (2%) had no known risk behavior.

The CDC does not include female-to-female sexual transmission as a reporting category, although the non-risk behavior of being an immigrant is. There are four cases with “unknown” transmission risk. To be fair, it is possible for a person with AIDS to die or refuse to provide information on risk behavior. Yet there is a significant difference in the CDC ‘unknown’ categories.

In the July 4, 1988 Morbidity and Mortality Weekly Report, AIDS statistics are reported for men, women, and children. Across the three largest ethnic categories, the unknown transmission group for men was about 3%, for children about 3%, and for women 8%. This 5% difference raises questions. What is different about reporting for women than for men or children? Some speculate that underreporting of stigmatized behaviors due to cultural differences is responsible for this difference yet this 8% persists across ethnic categories. Is that 5% difference where sexual transmission cases are falling or is it a statistical quirk? Nobody knows.

Being in San Francisco in the early 80’s was a confusing time. I heard about a few cases for the gay ‘flu’ but nobody knew what it was. I’m hearing the same tune again, not only from the CDC but also from the gay press. In a caustic retort to Minkowitz’ article the New York Native (2/27/89) states “three in 5,000 cases [of AIDS among women] is not exactly a frightening statistic….” I remember only too well when I only knew three men with AIDS. 3 cases frightens me.

Anger and rage aside, my personal and completely unsubstantiated opinion is that sexual transmission between women is most likely a rare
Don't Treat Me This Way

Foscarnet, DHPG and the FDA

by Terry Sutton
with Sean McShee, Tedd Siegel, and Eric Slade

[This is the first of a series on treatment issues. Terry Sutton (621-7996) is coordinating an ACT UP treatment issues group.]

CMV is a virus that seemed relatively harmless before AIDS. But up to 40% of PWAs have CMV infections, including dreadful manifestations such as CMV/retinitis - the infection of the retina that usually leads to blindness. Among the most common experimental treatments for CMV is the drug DHPG. But DHPG does not work for everyone, and cannot be taken with AZT.

People with AIDS and other life threatening diseases face a host of opportunistic infections, and in every case patients can and do fail on the experimental treatments. If a patient is not healed by the drug, or if it proves to be too toxic for extended use, he/she “fails” the drug. If there is another protocol for such people, it is called a “salvage” protocol.

There are two “salvage” protocols becoming available to “failed” DHPGers; foscarnet (a promising new AZT compatible drug) and intravitreal (a DHPG injection treatment, also AZT compatible). But the foscarnet trials have been delayed for months, and there will only be slots for several hundred people, despite the existence of thousands of “failed” DHPGers. While intravitreal trials have been occurring for over one year, the FDA recently stepped in and demanded controlled studies; this limited the number of slots available for intravitreal to just 30 people nationwide.

When they wrote the protocol, the researchers all knew that DHPG was often unsuccessful. There was no sense of responsibility to care for these people. Because of DHPG toxicity, people with CMV/AIDS have “failed” the DHPG protocols. I have not “failed” DHPG - - but because AZT and DHPG are not compatible, I am unable to treat the HIV infection itself. It seems absurd to save my sight only to die sooner. In the case of CMV retinitis these simply are not other treatment options. Foscarnet and intravitreal represent hope, but by FDA-rules, hope for a very few.

All protocols in this country must be designed with two tiers to incorporate those who have failed experimental treatment. This two-tier protocol design would give researchers access to “pure subjects” (Tier I) as well as offer potentially life-saving treatments to those with no other option (Tier II).

According to Harvard University, the number of people with AIDS on protocols in the entire country is 4,000 - the number of cancer patients on protocol is 40,000. Both groups face debilitating disease, even death. The current foscarnet study is offering only 28 slots.

All protocols must offer sufficient slots for patients who have no other choice.

[See related event in calendar 3-17. Next issue we continue to look at treatment issue problems and solutions.]
Events for Days (and Nights)

ACT UP events are italicized.


March 16 - ACT-UP General Meeting, 155 Eureka, 7:30.

March 16 - Forum on Prop. 96, 7pm Women’s Building, 3543 18th St., Sliding Scale.

March 17 - Forum on Needle Exchange, 101 Grove, Room 300, 9am to noon. Call 227-5507 for more information.

March 17 - ACT UP meeting with Nancy Pelosi about access to foscarinet for details call Terry Sutton (621-7996)


March 20 - Direct Action for Peace in El Salvador, 7am, Polk and Golden Gate, SF Federal Building. Lesbian/gay contingent call (821-9087).


March 25 - April 2 “Circle the Earth Workshop” Anna Halprin’s participatory dance ritual dealing with AIDS. Call 461-9479 for info.

March 26 - ACT UP presentation at A Different Light Bookstore, 489 Castro, 7pm

March 29 - “Come Out Hollywood”, Academy Awards Action by the Sisters of Perpetual Indulgence, UnInc. (626-9636)

March 30 - ACT-UP social, 7:30 pm, 155 Eureka, SF

April - Men Who Care About Women’s Lives is planning a candlelight march and civil disobedience supporting reproductive rights (337-2061).

April 2 - Keep Abortion Safe and Legal March, 11 am, Embarcadero and Market, SF; Rally 1:30 Civic Center, SF; Men who Care is organizing a men’s contingent call (337-2061).

April 5-9 - 11th National Lesbian Gay Health Conference, Cathedral Hill Hotel, San Francisco.

April 6 - ACT-UP General Meeting, 7:30, 155 Eureka, San Francisco.

April 6 - Report back from Durham Meeting to plan national lesbian Conference. Women only, 7:30 pm, 3543 18th, SF.

April 13 - ACT-UP general meeting 7:30, 155 Eureka, San Francisco; ACT-UP action committee project 8:30, 155 Eureka, San Francisco.

April 15 - Selection of one half of the ACT-UP Coordinating Committee by this date.

April 15-16 - Nevada Test Site Action, Direct Action to stop underground nuclear testing in Nevada. Lesbian/gay contingent being organized. Call Waiyde (861-2738).

April 15 - Chronic Fatigue Syndrome Conference, 9am to 5pm, SF Hilton. Its expensive; $75.

April 20 - ACT-UP general meeting 7:30, 155 Eureka, San Francisco. Deadline for articles for next issue of newsletter.

April 27 - ACT-UP general meeting 7:30, 155 Eureka, San Francisco; ACT-UP educational forum “IVDUs and AIDS”. Deadline for calendar continued on next page
Californians Taking Direct Action

By Sean McShee, notes by Tony R. and Billy Klub

The California Direct Action Network (C-DAN), a network of California lesbian/gay activists, met in San Francisco, February 18-19. The development of a statement of purpose precipitated an identity crisis. Is C-DAN a lesbian/gay liberation/rights or an AIDS activist group? After much debate the conference participants agreed that both should be equally emphasized.

The Conference selected four priorities for the upcoming year: 1. Health care funding in California, 2. Speeding up the release of California treatment drugs, 3. Opposing anti-lesbian/gay politicians, and bigotry, and 4. Fighting violence against lesbians and gays.

Another topic of discussion was how to be pro-active, rather than reactive to the next AIDS-phobic ballot initiative to appear. The Conference agreed to produce and distribute a general educational brochure to be used throughout the state to counter such future ballot initiatives.

The Conference also set up the mechanisms to produce an organizer's packet. Each local organization will draft their own packet, to be presented at the next conference. Arawn Elblyyn (SF) will be responsible for coordinating this.

The next conference will be held in Los Angeles on June 3 and 4. Call Arawn (863-5770).

Lesbians, continued from page 4

event at this time, and that other risk behaviors such as sharing contaminated needles and unprotected sex with men are the risk for HIV for women with a lesbian identity. In any case, safer sex guidelines are available for women. We don’t need to know whether female-to-female sexual transmission can actually occur and in what numbers to make decision for ourselves about safer sex. We have bleach for needles, condoms and dental dams, and each other. But frankly, as a researcher, I am disturbed by the chorus of ‘nobody knows’ when questions are posed regarding lesbians. Homophobia, sexism, a refusal to believe that lesbians have sex - these are the issues that are determining the scientific reporting categories of the CDC. We’ve been through this before, with great pain and anguish, and I don’t want to go through it again.

Calendar
Continued from previous page

items for next issue of newsletter.

April 29 - "We Won’t Take Four More Years”, March in San Francisco, 11 am UN Plaza (Market and 7th), multi issue, (415) 821-6545.

May 1-8 - ACT-NOW Educational Action - call the Hot Line for info.

May 9-15 - ACT-NOW action - call the hot line for more information.

May 13 - ACT-UP mailing party for newsletter. Call Sean (863-5245) for more info.

May 15 - Next newsletter out.

Committees and Caucuses

Action Committee: Steve 334-5926
Education Committee: Shawn 863-5245
Fundraising Committee: Niq 474-4154
Media Committee: Matthew 653-0654
Outreach Committee: Rick 552-1775

PISD Caucus Bridget 5526918
Women’s Caucus Kelly 282-0859
ACT NOW Rep Arawn 863-5770

(Some of these are changing soon.)
Continued from page 1. 

California Tainting Direct Action

The California Direct Action Movement is a coalition of organizations, activists, and individuals working to end the use of meat and dairy products in our lives. We believe that the use of animals for food, clothing, and cosmetics is unethical, unsustainable, and unnecessary. We are committed to creating a world where animals are valued for their own sake and not for their economic value.

The California Direct Action Movement was founded in 2010 by a group of activists who were tired of the way animals are treated in the food industry. We decided to take direct action to address the issue and to educate others about the plight of animals in the food industry.

We believe that direct action is necessary to bring about change. We are not afraid to take risks and to stand up for what we believe in. We are a diverse group of people and we come from all walks of life. We are united in our belief that animals deserve to be treated with respect and kindness.

We hope that you will join us in our direct action efforts. We welcome new members and we look forward to working with you to make a positive change in the world.
Zaps and Actions

A time capsule, containing 54 pieces of "endangered art" was carried through the streets of San Francisco, September 7 by artists and activists to its burial site next to the Arts Commission gallery. The march and ceremony, sponsored by the Bay Area Coalition for Freedom of Expression, Queer Nation/SF and ACT UP/SF's Propaganda Committee, targeted the real issues that drive the recent moves to censor and defund artists seeking grants from the National Endowment for the Arts.

The NEA controversy is a mask for a direct attack on lesbian and gay artists, says John Holland, of ACT UP/SF's Propaganda Committee. John Frohnmeyer recently denied funds to four artists, three of whom are gay and all of whom create works that deal with the politics of sexuality.

"Frohnmeyer, Bush and Helms are trying to legislate a cultural agenda," said Holland, "and this agenda calls for the elimination of diversity in the arts. The entire issue of NEA censorship is driven by racism, sexism and homophobia and most of the straight arts organizations are afraid to talk about it."

Helms' attack on what he calls perverse and obscene art, began in 1988 when he convinced congress to deny funds for AIDS education materials containing obscenity. ACT UP responds to this issue of arts censorship because AIDS art has consistently been targeted by the right-wing. ACT UP/ SF's Struzenberg said that, "AIDS is political, and..."

Oil is not a good lubricant

by Sean McShee

At press time, a Senate Subcommittee blocked release of $300 million in AIDS emergency funds to cities hardest hit by the epidemic. Of this amount $20 million is due to San Francisco. The stated reason was the sudden lack of funds. This may be the first of a new round of social service cuts.

The militarization of the Persian Gulf threatens to intensify the fiscal collapse of needed social services and to increase official encouragement of bigotry and sectarian violence.

US political dynamics are such that social services compete with the military for funding. The current political balance of power is that social services loose. With deficit spending, however, the competition extends into the future when the bills for the borrowed funds come due. An increasing share of public revenue becomes earmarked, not for a political choice, but to pay back this debt and its interest.

This debt-payback shrinking of the potential public funds combines with inflation to create the fiscal crisis of increasing social demands for declining social service.

To move from a hospice model of AIDS care to a treatment model means more funding for experimental treatment drugs, more people living longer with intermittent periods of debility that may last longer, and more people outliving their private health insurance.

Still the epidemic will grow as people turn symptomatic. Thus, the social service needs of HIV will increase drastically as the cost of Reagan's military buildup joins with the $500 billion Savings and Loan boondoggle.

On top of these fiscal disasters comes the threat of war in the Persian Gulf. Cost estimates of the Persian Gulf action range from $1 million a day
ACT UP Women Speak Up

by Crystal Mason and members of the Women's Action Committee

The following are excerpts from the position paper of the Women’s Action Committee and Crystal Mason’s introductory speech at the Aug. 30 ACT UP/SF meeting.

“I pledge to join others in fighting for all our lives and liberties during the AIDS crisis...”

This is how the AIDS action pledge begins. Out of the AIDS Action Committee came ACT UP/SF. The question today is whether ACT UP/SF remains committed to fighting for all of our lives? If we hope to beat this epidemic the answer must be yes.

For those of us committed to this fight, we know if the answer is no, years from now we'll still be in the streets demanding the same things we demand today.

“We believe the AIDS crisis calls for a broad movement actively engaged in ending the epidemic. We recognize that AIDS has had a devastating impact on the lesbian and gay community.

“We further recognize that the AIDS crisis disproportionately affects men and women of color. Any strategies to fight the crisis must incorporate these understandings.”

The above lines are also from the AIDS Action Pledge. Now is the time we must ask ourselves if we as ACT UP/SF really mean what we say or are we just being politically correct in saying it?

Political correctness is an empty plate to a hungry person.

What ACT UP/SF has claimed to be is the AIDS Coalition To Unleash Power. By choosing to be part of this coalition we all at least imply that we agree that we are just that, a coalition.

We as the Women's Action Committee understand what Bernice Johnson Reagon says when she speaks of coalition work being a struggle and we call upon other individuals within ACT UP/SF to recognize that “most of the time you feel threatened to the core and if you don't, you're not coalescing.”

The ACT UP/SF Women's Caucus and Women's Action Committee will fight to make sure ACT UP/SF truly acts as a coalition.

A coalition that is about ending the AIDS pandemic on a global level, and that includes—as we publicly say it does—fighting sexism.

AIDS is about all phobias and isms, including sexism. We all must be able to see this.

Sexism is about an unequal power dynamic, where men have the power and use it over women to keep women in check, to make women do, feel, think what men want us to. This organization which is overwhelmingly male has to constantly work against that power dynamic that sees empowerment as power over.

Men in ACT UP/SF have to keep checking themselves and each other to insure that words and actions are not sexist. Any time a man or a man act out that dynamic of power over a woman that is sexist. Even if men are apparently unaware of that fact that is sexist. When men deny that it is sexist, that is sexist. Playing out the male power against one woman disempowers all women, especially in a room where men often outnumber women ten to one.

Refusal to deal with these issues, or even acknowledge them is buying into society's erroneous images and is hindering the fight against AIDS. We the ACT UP/SF Women's Caucus and Women's Action Committee say, "Deal with these issues! Be a part of the coalition! Do not attempt to railroad your own agenda through by invoking the male power privilege."

As women we came, and still come, to ACT UP/SF and are, or become, educated around issues which particularly concern gay men. We know more about gay men than they know about us. We know that to be part of ACT UP/SF we must be allies to gay men, and be actively working on all of the issues that are part of the AIDS Action Pledge. We demand that the men in ACT UP/SF be allies to women and work on the issues that ACT UP/SF says it's working on.

We demand that sexism not be tolerated in ACT UP/SF. We demand our space as women, both white women and women of color, as lesbians, as AIDS activists, as political people, and as individuals. We demand acknowledgment of the work we have done.

We state that being an ally against sexism is not a simply refrain from blatantly sexist or misogynist language, but also a constant struggle, an active, ongoing, activity something that men need to do every day, every hour, every time men speak or act.

Fighting sexism means taking risks. It means being bold enough to call each other on sexism and owning your own sexism. It means struggling to unlearn what you've been taught and owning that being part of an anti-sexist coalition is a real struggle.

Whether this is now what you are about, or not what you plan to

Committees and Caucuses

Women's Caucus: 255-6758
Women's Action Committee: 255-6758
State and Federal Issues: 621-5689
Treatment Issues: 863-5770
TRAAC: 626-8548
Fundraising: 552-1775
Legal: 673-8452
Finance Committee: 673-2328
Committee Against Racism and AIDS: (CARA) 621-6865
ACT UP Network: 861-7505
People with Immune System Disorders: (PISD) 863-5770
Newsletter Committee: 863-6348

ACT UP/SF September-October 1990

ACT UP/SF is a diverse group united in anger and hope and committed to non-violent direct action to end the HIV epidemic.

The ACT UP/SF newsletter is produced by the Newsletter Committee of ACT UP/SF. The committee consists of Eric Slade, Mic, Sean McShee, Jonathan Arnowitz, John Holland, Alexa King, and Miguel Gutierrez.

Special Thanks to Carol Schneck for deciphering our handwriting and proofing our mistakes.
It's Boycott Time for Miller, It's Bedtime for Jesse

by Jonathan Arnowitz

ACT UP member Bill Haskell observed that AIDS—not beer—is on the agenda of ACT UP, so we strongly question the motives of lesbians and gay men who are fighting so fervently for Miller Beer yet contribute nothing positive to the lesbian and gay community. Bill has done a laudable job keeping the boycott focused on the enemy: Jesse Helms.

The reasoning behind the Miller boycott is the simple fact that the proceeds from Miller Beer support the arch conservative homophobe Sen. Jesse Helms (R-N.C.).

Do you want to support Jesse Helms? If the answer is no, you boycott Miller Beer, the same as you would boycott Marlboro cigarettes. This is a simple action anyone who drinks or smokes can take to actually do something to fight Jesse Helms. There is the pitiable claim that both Philip Morris and Miller Beer have contributed to AIDS charities. It has continued on page 6

Who represents the community?

It came as no surprise to find full page advertisements for Miller beer in recent issues of The Sentinel and the Bay Area Reporter. Their biased reporting against the Miller boycott almost always characterizes the boycott as poorly conceived and unsupported—seems to be motivated by something other than pure reason.

Fortunately for those of us who hate Jesse Helms, the boycott is succeeding despite attempts by the Sentinel and the Bay Area Reporter to tell us otherwise.

After a recent meeting with Miller, the Board of Directors of the Castro Street Fair stated, "The Castro Street Fair can’t be bought," and dumped Miller as its official sponsor.

Meanwhile, endorsements for the boycott come from all corners of the nation, including the Human Rights Campaign Fund and the United Farm Workers of Los Angeles.

These papers even claim that we are wrongfully influencing "the community" as if we were not part of that community ourselves.

We believe that as individuals we have a right to protect ourselves and "our community" from homophobes like Jesse Helms. Yet "our" newspapers believe that they have the first and last word in deciding who the community is and what it wants. But they obviously do not represent the community when they ignore the support the boycott has in San Francisco.

The biased coverage angered New York's Outweek magazine enough to write a full page editorial in its August edition: "Suddenly the gay press was full of earnest, hand-wringing editorials questioning whether anyone in the community has the right to launch a boycott just who is empowered to call one off and who presumes to impose political cohesion on gay organizations that choose not to honor the boycott.

Pardon us while we puke. Such self-serving garbage caused Adweek, which monitors these matters, to report that industry observers continued on page 6

The Sullivan Disruption: No Apologies

On the last day of the Sixth International Conference on AIDS, activists from across the country disrupted the conference's closing speech by Secretary of Health & Human Services Louis Sullivan.

Though the action targeted the Bush Administration's pitiful response to the AIDS pandemic, some saw the action as racist because Sullivan is a black man. The following is a speech Adelle Morrison and Neal Murray wrote in response.

We are here today for two reasons. First to make an attempt to share the views and politics of people of color AIDS activists. And second to clear up what has obviously been a misunderstood action of ACT UP/SF at the Sixth International AIDS Conference.

We as members of the People of Color Caucus of ACT UP/SF find it discouraging that some community members talk about ACT UP as if we were a bunch of gay white men.

It has yet to be noticed there are women and men of color who are AIDS activists and who work as a part of ACT UP across the globe.

Maybe you didn't notice that the Sullivan demonstration was initiated by people of color from ACT UP Chicago, New York, LA, and San Francisco. You don't notice us because the media neglects to focus on the community at large wants to accept it, when you speak of Sullivan's community, you speak of our community.

Yes, we participated in the Sullivan demonstration. And we are here today to tell you we were there. Yet, we continue to be invisible because we are Black, Latin, Asian, Native American—lesbians, gays and bisexuals.

Our current numbers may be small within ACT UP compared to the thousands of white AIDS activists. But we are out there. We were at Sullivan's speech. We are active, we are vocal, and we are committed.

We are committed to doing something for our community as part of a coalition of individuals committed to national health care, committed to a much larger allocation of national, state, local budgets to health care and all medical research.

And above all we are committed to ending the AIDS pandemic. We will continue to be there, as will our Asian, Latin, Native American, Black and white brothers and sisters.

continued on page 5
SCENES from the STREET
the sixth international AIDS conference

June's International Conference on AIDS brought activists from around the world to San Francisco for a week of inspiring, empowering actions. Daily demonstrations were joined by many Conference attendees. ACT UP actions kept the crucial issues of the day on the front pages of the daily papers.

During the week over 300 people were arrested on charges ranging from disturbing others to blocking. Most of the defendants were sentenced to 10 hours of community service work, while three faced more serious charges. But the larger group threatened to clog the system unless everyone received the community service sentence. In August the court reconsidered, and all defendants were granted the lighter sentence.

Photos by Rick Gerherter.
Treatment Issues Pursuing DDI, DDC

by Michael Wright

treat vt: to deal with in order to relieve or cure
issue vt: to put out, deliver for use, put into circulation.
treatment issues: a committee of ACT UP/San Francisco focused on the availability and accessibility of a variety of treatments for HIV and its related opportunistic infections.

The ACT UP/SF Treatment Issues (TI) committee has quadrupled in size since the 6th International Conference on AIDS. TI held two 6-hour workshops highlighting treatments and problems of access both for new members and interested members. Topics included "The Biology of HIV," "The Structure of the National Institute of Health’s ACTG (Aids Clinical Trial Group)," "Alternative Treatments," as well as forums addressing the problems of accessibility to treatment and the differing courses of HIV disease in women and people of color.

We are actively agitating the FDA to release both DDI and DDC in 1990. We already have more clinical data on DDI and DDC than existed on AZT at its approval. With thousands of people who cannot tolerate AZT, the development of AZT resistant strains of HIV and the recent reports of increased lymphoma in long-term survivors (which has not been directly attributed to AZT) anything other than immediate release of these drugs can only be viewed as continued government sponsored genocide. Watch for upcoming major TI actions!

TI has held meetings with drug companies involved in HIV both to encourage drug development and approval as well as to educate them in issues of treatment protocols. The details of how a drug trial is conducted, the protocol, has a direct effect on the number of people who are eligible to participate. By expanding inclusion criteria and limiting exclusion criteria, studies are made more accessible to all. The selection of co-investigators, participating hospitals, and research protocols strongly affects the outcome of the trial.

"Anything other than immediate release of these drugs can only be viewed as continued government sponsored genocide."

Sullivan, from page 3

Secondly, we know that not everyone agrees with the tactics of ACT UP. Yet, as AIDS activists, we are a part of an international body of individuals who are united in anger and in action to end the AIDS pandemic. We do so by calling attention to the right of health care for everyone regardless of age, race, ethnicity, national origin, class, sexual orientation, language, disability, or the ability to pay. The demonstration against the Bush Administration on the last day of the Sixth International AIDS Conference has caused a stir and has some people calling for condemnation of ACT UP for being racist.

What we don’t understand is how our views, very vocal, very loud, yes very rancorous, very angry, and maybe even rude, demonstration, designed to call international attention to the genocidal inaction and hypocrisy of the Bush administration, was a racist act.

Our focus is on the Bush administration. They chose to be represented at the conference not by Bush himself but by Health and Human Services Secretary Dr. Louis Sullivan. We ask: Where is George? The President was off to North Carolina at a fundraiser for Jesse Helms. The fact that Louis Sullivan is black had nothing to do with why we chose to drown him out. The fact sheet distributed before the action explained why we chose to do what we did.

“Project Count Down...18 Months” specifically designed to finding treatments and prevention for all the major opportunistic infections by 1992.

Gulf, from page 1

militarism means hostility towards those perceived as ‘weak’ - the infirm, the disabled, and those who cannot pass as butch.

Lesbians and Gays are not the only groups to be ridiculed in cartoons and movies - Arabs have been the brunt of editorial cartoons, a host of stand-up comics, and numerous movies. Since rights exist only insofar as they extend to the most despised, we may have to defend the rights and dignity of Arab Americans.

But we cannot romanticize any side in this conflict. Saddam, like Bush, is a vile, authoritarian militarist. Kuwait has been ruled by a corrupt monarchy. This time we need an anti-intervention movement without heroes. Both HIV and militarism cut across social issues - sexuality, gender, race, and class, among others. Analysis is looking at issues separately. It is necessary to take things apart in order to fix them. Synthesis is seeing interconnections. It is necessary for making alliances, building coalitions, and reconstituting society. We need both.

U.S. SPENDS MORE IN 5 HOURS ON DEFENSE THAN IN 5 YEARS ON HEALTHCARE
Bedtime for Miller, Helms, from page 3

already been established that their claims are not only inflated but also of dubious veracity.

Even if, for the sake of argument, we accept Miller's claims of financial contributions, it would be cold comfort indeed to tell the people who are right now dying of AIDS that the funders of the major anti-AIDS agenda are also contributing a pittance to AIDS services.

One thing that we think that at least Miller Beer can do is publicly declare what they claim they believe privately: That they abhor Jesse Helms as well as their parent company's contributions to Sen. Helms. If they really feel oppressed they have an obligation to ACT UP to fight back, and all we are asking is for them to do their part. What these beer executives fail to understand is that we are dying, and while we are risking our lives the least we can ask of them is to risk their corporate child/ parent relations. Until Miller acts up we are not going to drink their beer, it is as simple as that.

Other people have dogmatically claimed that Miller Beer is our friend. They point to the Lesbian/ Gay Parade sponsorship by Miller Beer. This is a simple marketing strategy that has made a tremendous amount of money for Miller Beer. Which raises the precarious question: why are these people fighting for Miller Beer in the first place? We are pursuing an AIDS agenda and we suddenly find ourselves beseeched with not far right extremists, but far-beer extremists.

Apparently B.A.R. reporters, Sentinel editorials and Parade committees find the politics of beer more lucrative than the politics of combating AIDS. So as far as being a friend of the community, ACT UP believes that simply reaping the benefits of the profits generated by the parade, does not a friend make.

It is unacceptable that the Miller Brewing Company and Philip Morris feel they can give us a little money with one hand, and bury us with another.

That is how we view the Philip Morris boycott, and on this issue ACT UP would rather fight than switch.

Community from page 3

ers 'aren't so sure' that the gay community has enough 'mettle as a consumer bloc' to effectively boycott Marlboro and Miller. With Miller frantically trying to place full page ads in gay papers and with financial greed frequently overwhelming community self interest, we're not so sure either.

Thousands of people across the country are boycotting Miller and Marlboro. If we remain united, we will win.

Zaps and Actions from page 1

gent of ACT UP members. This year's march was held in memory of ACT UP/SF member John Belkus, one of the founders of the AIDS/ARC vigil who died earlier this year.

• September 5: TRAAC sponsored a demonstration at San Francisco General Hospital

• September 13: ACT UP/SF members joined in the GLAAD Textbook demo to get Gay and Lesbian information into textbooks and the California school system.

• September 15: TRAAC sponsored a demonstration at San Francisco General Hospital

• September 19: State and Federal Issues Committee planned a huge demonstration against George Bush who was speaking at the Fairmont.

John Belkus (1947-1989), a founder of the ARC/AIDS Vigil. The March for National Health Care was held in his memory.
A Whore's Own Story

by Jezebuck, a pro-sex sex pro

My name is Jezebuck and I'm often confused with the man who draws me, since I only exist in cartoons and a soon to be released calendar - here I am promoting myself again. Such a shameless whore! I briefly want to clue you in to my experience as a whore and an AIDS activist and the resulting intercourse. (I shall also warn you that prostitution and its discussion is heavily laden with puns.) The foremost topics that come to mind are stereotyping, scapegoating, responsibility and my own attitudes towards sex and economics. I use the term whore over hustler since "hustler" implies I'm trying to shorthange somebody. Whores are also stereotyped as oversexed vessels of disease who are desperate for money and drugs, and just overall unsavory.

There are many types of prostitutes, just as there are many reasons for becoming a prostitute. Additionally, there are many people who don't consider themselves prostitutes, yet use sex to get paid - some reward, maybe not in cold cash, but nevertheless payment. It's not healthy to generalize.

Since prostitution involves illegal activities, many of us are understandably skittish about our work. This fear keeps us isolated because of lack of trust for others. Add to this the negative connotations of wholedom, and you come up with a weak population, certainly not a community of whores. We have been easy prey for the history of hysterical effects of society's neurosis with sex. We're blamed not only for disease but breaking up marriages, increasing the crime rate, fostering irrelevant attitudes toward religion, devaluing property in Haynes Valley, etc. Folks like to point fingers, and we're an easy target. Naturally, repressive actions touted to stop the spread of HIV are aimed at us. We have suddenly become one of the culprit communities responsible for transmitting the pandemic to the "general population." The discussion that never ensues when the word "responsible" comes around is that everyone who is having sex is responsible for having safe sex. If you can't get a hold of safe sex information in your hometown in a safe environment, if you were never taught safe and positive sex at home or at school, if you choose to live your sex life in a state of denial, that's not the prostitute's responsibility, unless of course you're a prostitute who runs public health policy, has children, or can consult a crystal ball every time a client seeks you out. Overwhelmingly, the Johns are the ones pressuring the whores to have unsafe sex, and use money as their persuasive tool. Not all of us are in a position where it's easy to turn down a tempting sum of money, yet we are the punitive dart bastards.

Not all hope is lost for us ladies-and-gentlemen-and-those-in-between of the night. Recently I co-hosted a town meeting for whores and updated those present on prostitution laws and the recent mandatory HIV testing requirement for those convicted of soliciting for sex. Some of us are watching a test case in Stockton. Other whores have had their civil rights stripped, but because of our lack of community, our advocates are not finding out until after the fact. With work, the networking that developed from the town meeting will harden into some stiff opposition to our current legal situation, HIV testing and otherwise.

Well, I've got to get back to the drawing board.

Editor's Note: ACT UP recently had an educational on sex worker's issues and rights and conditions, and continues to advocate a pro-choice, pro-sex, pro-sexworker agenda.

WHO AIDS day focuses on Women

by Alexa E. King

December 1st is International AIDS Awareness Day, and the World Health Organization has chosen "Women and AIDS" as this year's topic. While this selection is gratifying in that it acknowledges that women do indeed get AIDS and die from AIDS, it also calls to light the omissions, misinformation, and denial which have kept the issue of women and HIV from being properly addressed.

In Africa, where heterosexual transmission is a major factor in the spread of AIDS, about 50% of HIV+ people are women. In the United States, AIDS is currently the number one cause of death amongst women aged 18-34 in several cities, including New York. Of course, up to 80% of known cases of HIV infection in American women occur among women of color, primarily African-Americans and Latinas. The forces of global sexism and racism have combined to keep women from receiving the education, support, and services we need.

December 1st provides ACT UP Network (formerly ACT NOW) with an opportunity to plan a major national demonstration. ACT NOW has decided to target the Center for Disease Control (CDC) in Atlanta, in an effort to get the CDC to change its official definition of AIDS. The CDC definition of AIDS does not include any gynecological opportunistic infections (OIs). This is a result of AIDS in North America first appearing and being studied among overwhelmingly male groups: gay males, injection drug users (75% male), and hemophiliacs (a male-gender-linked trait).

This definition has institutionalized a male bias which eliminates women from AIDS statistics, treatment, and social service benefits. Because the progression of HIV infection in women does not follow this male-defined model, women with AIDS do not fit the official definition of AIDS. They remain officially HIV+ and are thus denied services and funding. As a result, women with AIDS die four times faster than men with AIDS.

ACT NOW will demonstrate at the CDC in Atlanta to protest the sexist definition of AIDS. The women's caucus of ACT UP San Francisco is planning a local action to coincide with the demonstration in Atlanta and other local actions throughout the country.
Keep ACT UP, Acting Up

ACT UP/SF stays busy day and night pointing out what's wrong and demanding what's right. We're loud, contentious and effective.

We went to Burroughs-Wellcome to expose AZT price-gouging, we joined with nationwide ACT UPS in shutting down the FDA to demand an end to deadly drug policies, we're vigilant in demanding an end to bigoted immigration policies. And each week we take on new challenges....

We need money to keep our efforts going. No one in ACT UP gets paid. Every dollar we receive goes directly into fighting the AIDS epidemic through meetings, demonstrations, and actions.

Give what you can, and help keep us Acting Up.

Here's some money, keep up the good work!

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Concord: “A Human Rights Emergency”

by Michael Thompson

The California State Association of Human Rights Commissions has described Concord as being in a human rights state of emergency. The lynching of a gay black man three years ago is merely one graphic and tragic reminder of this crisis.

The Concord City Council unanimously passed an ordinance guaranteeing the rights of PWAs in employment, housing and access to city services, but a petition was presented to the city clerk calling for the repeal of the ordinance. Upon validation of the petition, the city has two options - repeal or send it to the voters.

At the beginning of June, the Local Issues Committee was charged with researching the situation in Concord. The petition was sponsored by Rev. Lloyd Mashore of the Concord Christian Center, a fundamentalist Christian church with ties to the TVC (see article, page 4). While Mashore claims he initiated the petition because he felt the ordinance catered to a small special interest group, the real motivation of his actions are evident. He and the TVC are using the repeal to advance their agenda of bigotry and homophobia. Their real goal, is to create an AIDS-free, gay-free zone in Concord.

Zaps & Actions

by Eric Slade

The recent restructuring has greatly benefited ACT UP SF. ACT UP people have been outside on the streets protesting and inside offices negotiating.

ARC/AIDS Vigil Attack, June 9. Gay lawyer Walter Kaplan attempted to have the police close the ARC/AIDS vigil. ACT UP people helped put the word out on the street quickly and gathered enough supporters to forestall police action. The vigil is still the longest AIDS protest in the world (since October ’85).

UCSF Placebo Action, June 17. Around 75 people protested UCSF’s placebo trial testing on babies and infants with AIDS.

In one trial, a group of symptomatic babies with AIDS is connected to IV infusions of placebo for a minimum of three hours. The other group is treated with IVIG. Most of the children in the study are from low income and people of color families for whom this is their only chance of receiving treatment.

In a meeting before the action, UCSF’s Dr. Diane Wara agreed that ACT UP/SF raised valid concerns and promised to bring the concerns to the NIH the following week. In a meeting later in the month, Fauci

continued on page 3
Is Anthony Fauci On Track?

by Eric Slade

National Institute of Allergies and Infectious Diseases (NIAID) Director Anthony Fauci used his keynote address at HIV Treatment Awareness Week (June 22-25 at Civic Auditorium) to unveil his new plan for “parallel tracks” in drug testing that would loosen the strict entrance requirements, while still allowing “good” scientific trials to take place. He says his new plan could allow more people access to experimental drugs.

Afterwards approximately 12 ACT UP members had a private meeting with Fauci. They questioned him on a number of issues, including his proposed parallel track plan.

This progress seems promising. Fauci is finally acknowledging the need for wider access to unapproved drugs and talking about a major policy shift towards wider access.

But there are problems with Fauci’s plan, problems unreported in the mainstream press:

1) Although Fauci’s talking about loosening requirements to let more people in, he’s not loosening them that much Fauci stated. “I’m not talking about thousands of people.”

2) Fauci doesn’t actually have the power to decide that this plan is going to happen.

3) If the drug companies don’t like it they do not have to cooperate. (We discussed with Fauci legislation that would force companies to comply with a plan like this. Fauci called the legislative solution “a long shot” but worth working on).

ACT UP wants everyone to have access to whatever drugs they need, and we may not want to put energy into a plan that just gives treatments to a few more people. Fauci believes it’s worth our attention because it will convince drug policy and protocol designers that this wider access can still be coupled with sound research.

On July 13, after discussions with Fauci, Bristol-Meyers announced it will release, at no cost, dideoxyinosine (ddI) to any PWA who needs the drug and doesn’t qualify for ddI testing protocols. ddI is a promising antiviral that appears to be as effective but not as dangerous as AZT. Bristol-Meyers appears to be embracing, at least in spirit, Fauci’s parallel track proposal.

But as ACT UP’s Michelle Roland points out, many details, such as who will actually qualify for ddI, have yet to be worked out. Roland is pleased Bristol-Meyers is agreeing to the parallel track plan in spirit. “If they agree in spirit,” she says “it’s easier to attack them later if they come out with bullshit.”

The Treatment Issues Committee is meeting with Congresswoman Nancy Pelosi in preparation for hearings (7/31-8/1) on Fauci’s plan in Washington D.C.

Our Goals and Demands

ACT UP (the AIDS Coalition to Unleash Power) is a nonpartisan group of diverse individuals united in anger and hope. We are committed to direct action to end the AIDS crisis. We demand massive governmental funding for research, health care, education, anonymous testing, and treatment. The research for treatments, vaccines, and cures should be centrally coordinated and publicly accountable to the communities most affected. We demand free nationalized health care guaranteeing equal access, regardless of ability to pay. We demand a federally-funded sex positive education program to promote safer sex. We demand that information on needle hygiene be made available to all needle users. We further demand that addiction treatment/recovery programs be expanded and available to all regardless of ability to pay. We further demand that these programs be instituted in a culturally sensitive international program.

ACT UP/San Francisco grew out of the AIDS Action Pledge, implemented in 1987 to respond to the deplorable government and private sector response to this crisis. We’re part of a growing worldwide movement, coordinated nationally through ACT NOW (AIDS Coalition to Network, Organize, and Win). ACT NOW’s number is (415) 861-7505.
admitted that he has moral problems with the study.

Foscarnet Action, June 21. Fauci’s visit to SF provided impetus for a demonstration at the Old Federal Building. Demonstrators were prepared for civil disobedience, but since the HHS agreed to support our call for compassionate access to foscarnet, the action turned into a rally, picket, and die-in.

Of the two drugs currently available for treating CMV retinitis (foscarnet and DHPG), DHPG cannot be taken with AZT. Thus for many foscarnet is preferable. In many European countries foscarnet has been the primary therapy for CMV for some time.

Foscarnet’s manufacturer, Astra Pharmaceuticals, refuses to release the drug on compassionate use and NIH refuses to open up wider foscarnet trials. Astra’s Boston representative Cheryl Carroll’s toll free number is 1-800-225-2787.

INS Actions, Part I, June 22. Several people from ACT UP’s State and Federal Issues Committee disrupted an INS Conference at Stanford. They risked arrest by seizing the stage in order to bring up HIV issues. They were not arrested and were offered their money back.

Part II, June 23. ACT UP staged a bilingual demonstration at the Immigration and Naturalization Service Headquarters in downtown S.F. 50 protesters were on hand to condemn the INS policies regarding HIV, and called for an end to mandatory testing as well as forced deportation of immigrants wanting to legalise their status.

Lesbian/Gay Freedom Day, June 25 ACT UP/SF had a large, spirited presence in this year’s parade. Crowd response as ACT UP marched by was overwhelmingly supportive.

At the rally Arawn Eiblyhyn, ACT NOW national coordinator spoke from the Main Stage. The ACT UP booth had people lined up all day buying T-shirts and buttons. Now that they have the right outfits, perhaps we’ll see them at the meetings and actions...

Concord July 2 - About 70 activists including, ACT UP people, demonstrated outside the Concord Christian Center where the repeal of the AIDS anti-discrimination ordinance is being organized. ACT UP people have also been attending Concord City Council meetings to press for the rights of PWAs.

Webster Decision Action - July 3. ACT UP people were and gay activists. In fact, Concord activists asked for ACT UP SF to come in and help organize that opposition. As AIDS activists concerned about securing the rights of PWAs regardless of city limits, we accepted the challenge.

Our goal was simply, to begin to provide a vocal, visible and unified opposition to Mashore and the TVC. To start, we attended two city council meetings in June to speak in support of the ordinance and announce our presence and

ACT UP/SF's Jo-Carrol and friend Jayme at the June 17 UCSF action protesting placebo testing on infants with AIDS. Protestors pointed out that babies receiving prolonged IV treatments are at high risk for infection and that babies can’t give "Informed consent."

among the 2000 protesters gathered at the Federal Building for over 5 hours in response to the sharp curtailment of abortion rights by the current Supreme Court.

July 13, Pro-Sex, Pro-Choice: ACT UP/SF Women’s Caucus, responded to the Webster decision and Deukmejian’s budget cuts to the Office of Family Planning. 15 people blocked the men’s room at the California State Building for 1 1/2 hours, to dramatize how someone can regulate access to services and facilities that should be up to individual choice and discretion. Six people were arrested and have a court date Aug. 16th. Plans for future actions by the Women’s caucus. Call Bonnie at 346-3041 for info.

ACT UP/SF was also represented at the Father’s Day March for Women’s Lives, Bay Area Coalition Against Operation Rescue clinic defense actions, White Night Memorial March and the Fat Dykes “Let It All Hang Out Day” on June 17. ACT UP people and t-shirts were also well represented at the Living Sober conference.

interest. Secondly, we staged a boisterous and lively action at the Concord Christian Center on July 2. We also mailed 30 letters of support for the ordinance and executed a phone zap. On July 11, the Concord City Council, under pressure from local East Bay Activists and ACT UP SF, voted to place this ordinance on the November ballot. This will be the first time that voters will vote on HIV discrimination issues. People in Concord will need money, help and energy. Call the events line (563-0734) for more info.
**TVC Guide**

**Who's Behind The Mess In Concord?**

by Michael Thompson

We are facing a formidable enemy in the fight for human rights and the end of bigotry. The Traditional Values Coalition (TVC) is broad based, elusive and well financed. They are also armed with an agenda of moral absolutism which excludes all people not conforming to its strictures.

The TVC is headed by Lou Sheldon in Orange County. Their agenda is clear and precise. They want to deny equal civil rights to lesbians and gays, abolish a woman’s right to choose abortion, remove sex and AIDS education from the schools (and replace them with Christian prayer), and a host of other rightwing fundamentalist Christian issues. Most recently, factions of the TVC pressured the Santa Ana City Council to reject a permit for the Lesbian/Gay Pride Festival, and the Orange County Board of Supervisors to defeat an AIDS rights ordinance. They are also active in the battle to shut down LA’s Project 10, a school program for gay youth.

Progressives have been shocked by the effectiveness of the TVC and have had trouble mobilizing effective opposition. In fact, what we are seeing is the use of our own coalition building strategy. The TVC draws on the resources of national right-wing groups and then disseminates the information and strategy among grass roots, locally based right wing groups. Their most effective tool has been using the pulpits of fundamentalist churches to deliver calls to action. Our local example is the Concord Christian Center and its Reverend Mashore.

Concord Mayor Colleen Coll calmly explains to ACT UP/SF members why she was the only person on the city council who voted to dump the city’s AIDS antidiscrimination ordinance. The TVC is fighting to defeat the ordinance.

There is no mystery in the TVC’s tactics, agenda or ability to mobilize. They are drawing on the resources, fundamentalist Christian fervor, credulity and bigotry of the same people who send their millions to TV evangelists. In fact, the “fall” of several of these “spiritual leaders” has left a vacuum which the TVC has readily filled.

In light of this, it is easy to see why Jerry Falwell has disbanded the Moral Majority. It has done its job. Its beliefs have been disseminated over the country.

What can we, as activists, do to defend our rights and secure those yet to be obtained? Quite simply, we need to energize, mobilize and ACT UP more than we ever have. We cannot trust “our” lobbyists and “our” politicians to “do the right thing.”

**Here's Some More Hateful Christians...**

by Sean McShee

The San Francisco Domestic Partners Ordinance has sparked enough anger among religious fanatics and nuclear family chauvinists to threaten a repeal initiative. This ordinance would allow unmarried partners, who register their relationship, certain rights usually reserved for ‘married couples’: hospital and jail visitation rights, and bereavement leave among other rights. City employees would also be allowed to register their partners onto the city insurance policy, but would have to pay their own premiums.

Organizing the repeal have been the Rev. Charles McHenny, Rabbi Feldman, the Proud Eagle Forum of Menlo Park and the local Catholic Arch-Diocese. McHenny (1st Orthodox Presbyterian Church of the Sunset) is a major activist among local fetus fetishists. He operates a right-to-life indoctrination center which masquerades as a pregnancy clinic. Local priests urged parishioners to sign the petition for economic, if not moral reasons. The Proud Eagle Forum is Phyllis Schaffley’s organization.

Petitions were filed with the Registrar of Voters. So we will be facing this initiative in November. Louise Renne has suspended the registration of partners pending the verification of signatures on the petition.

The Domestic Partners Coalition has formed to work to retain the ordinance. For information call Derrick or Jimmy at 863-4038.
CFS: Another Immune Disorder

by Bridget Lawhon

Chronic Fatigue Syndrome (CFS) is a complex illness that triggers an imbalance in one’s immune system. Why the immune system becomes triggered isn’t clear - it could be due to a virus, environmental factors or a genetic predisposition. CFS presents with a multitude of symptoms from incapacitating fatigue to neurological disorders. It is thought to be viral in nature but the exact cause is yet unknown. It can resemble a flu or a case of mononucleosis that never goes away. The symptoms wax and wane but are often severely debilitating and may last for years.

Research shows that many people with CFS have high levels of antibodies to viruses such as Epstein Barr, Cytomegalovirus (CMV), Herpes Simplex and Measles. The Epstein Barr virus, which is responsible for mononucleosis, was at one time thought to be the cause of CFS but is now considered to be an activated virus due to the immune dysfunction rather than the cause of it. Possible causative agents for CFS being researched are HHV 6, Human Herpes Virus 6, the family of adenoviruses (which affect the respiratory system) and other yet unknown viruses. Research also shows that in time people with CFS begin to produce antibodies against their own cells, as seen in other autoimmune diseases.

Right now, there is no definitive test for CFS which is also known as Chronic Fatigue Immunodeficiency Syndrome (CFIDS). Instead most diagnosis is based on a working definition developed by the CDC (Center for Disease Control). To meet the definition one must fulfill two major criteria: 1.) New onset of persistent or relapsing fatigue that does not resolve with bedrest, and 2.) Exclusion of other plausible disorders by thorough evaluation.

People with CFS/CFIDS are not taken seriously by the medical profession. They are not recognized as having “real” illnesses. They are often misdiagnosed with hypochondria, psychiatric disorders, hypoglycemia, mononucleosis, influenza, rheumatoid arthritis or multiple sclerosis.

Limited epidemiological studies suggest that the population with CFS/CFIDS falls largely within the ages of 22 to 44 with women outnumbering men, three to one. To date approximately 10,000 people have been actually diagnosed with CFS/CFIDS. Many others may have it without knowing it. Since the cause of CFS/CFIDS remains unknown, it is also unknown how it is transmitted. Whether a person develops this disease is believed to be due to a range of factors: how often they were exposed to the yet unknown causative agent, the overall strength of their immune system and their genetic background.

Within those with CFS/CFIDS, there is a spectrum of severity. Some people get very ill for a time and recover. Some people become ill and are well enough to function but do not recover. Others get very ill, become quite disabled, and remain chronically ill. The number and severity of symptoms may vary from one to another.

No clear treatment cures CFS/CFIDS. Control of the symptoms is the present aim of treatment. Acyclovir, a drug used to treat herpes, is helpful to some. Anti-depressants and histamine-blockers are also helpful in reducing symptoms. When the thyroid is affected, Synthroid is often taken. Various anti-inflammatory pain relievers are useful for the muscle, joint and bone pain. Acupuncture, stress reduction, herbal treatments and nutritional support have been beneficial for CFS/CFIDS.

Limited research funding has delayed the possible identification of a causal agent. The CDC is conducting epidemiological surveys and the NIH (National Institutes for Health) has committed minimal scientific support to this disease. CFS affects more women than men and historically diseases that affect women are not treated seriously by the medical profession. CFS/CFIDS has reached epidemic proportions in this country over the past 4 years. We as a society are slow to recognize epidemics. Our fear and our denial cause us to discount them in their early stages. This is particularly true as the CFS/CFIDS epidemic follows the AIDS epidemic.

People with CFS encounter great difficulty obtaining proper diagnosis and treatment due to the skepticism, misinformation and ignorance of public health officials, researchers and doctors. We in ACT UP need to fight this ignorance and fear. Hopefully, this article will educate us about this disease and we can then begin to pressure the CDC and the NIH to mobilize towards research and treatment.

California Abortion Rights In Danger

By Sean McShee

In the wake of the recent Webster decision we can expect a plethora of bills regarding abortion in the California Legislature in October. Two major abortion court cases provide the most direct challenge within California to reproductive rights issues:

Medical Funding. For the past eleven years the California Legislature has voted to ban the use of Medical funds for abortions. And for eleven years the courts have ruled this unconstitutional. The post-Rose Bird California Supreme Court has refused to hear these cases. The Webster decision, however, opens up a legal precedent for upholding the ban on Medical funding for abortions.

Minor Access. The legislature recently passed a law requiring parental consent, or judicial bypass, for underage females. There will be a hearing on this case in the First District Appellate Court on July 26.
On the Floor and Off the Wall
by Sean McShee

This is the beginning of a column to keep people updated on state and federal legislation. If you want to push for or against any particular piece of legislation, you should refer to it by the items in parentheses: AB or SB (Assembly or Senate Bill), then a number, and finally the name of the author.

The State AIDS Budget- Deukmejian has once again demonstrated his commitment to seeing thousands of gay males, IV Drug Users and others die by slashing the proposed $200 million AIDS budget. Particularly hard hit were the Early Treatment Centers (see below), cut by 90%. These cuts can be overridden but not without lots of pressure, particularly from outside the lavender belt of West Hollywood, and S.F.

Early Treatment Centers- (AB-1600, Speier) Establishes early intervention projects statewide for people with HIV, monitoring health and providing treatment (including AZT, & Pentamidine). Funded both publicly and through private insurance. [The funding for this bill was gutted by Deukmejian's veto.] Creates an oversight committee which will include Community Based Organizations and people with HIV. This has passed the Assembly and is now in the Senate. Quentin Kopp's vote (I-SF) is not considered definite.

Experimental Treatment Payment- (AB-1625, Burton) Currently health care facilities are not reimbursed for non-pharmaceutical costs in investigative treatment. Allows health care facilities to bill Medi-Cal for such services for both in-patients and out-patients. Passed the Assembly and is now in the Senate.

Unfair Insurance Practices- (SB-1328, Marks) Would make it an unfair insurance practice to deny benefits after a diagnosis of AIDS or ARC if the delay is for the purpose of investigating whether this was a pre-existing condition.

Passed the Assembly and is now in the Assembly Finance and Insurance Committee.

Doolittle is the second most powerful Republican in the state Legislature and the equivalent of Helms. He has at last count five HIV related bills on the floor ranging from the mildly offensive to the truly hideous. Parts of his earlier bills became Prop 102; Parts of these could become 'Son of 102'. Beginning with the mildly offensive.

Transfusions- (SB-37, Doolittle) Would require doctors to warn patients about the risk of transfusions.

Sex Education- (SB-7, Doolittle) Prohibits education about sex or homosexuality without written parental consent. (A TVC goal, see article page 4.)

Prisons- (SB-38, Doolittle) Requires mandatory testing of persons entering state prison or a narcotics facility. Authorizes testing of current inmates. (quite likely to pass)

School and Parks- (SB-39, Doolittle) Requires testing of all school, school transportation, community college, recreation service, parochial and nursery school employees, and children in child health programs. Permits any child to be tested entering any public school.

Sex Acts- (SB-40, Doolittle) Makes it a felony (of 3,5, or 7 years) for any knowingly anti-body positive person to have sex without informing their partner(s).

Among Federal legislation one bill is dangerous, is likely to move out of committee soon and has gotten very little publicity. The Rangel Bill (HR-2097, Rangel) would bar federal funds from programs that either supported needle exchange, bleach distribution or educated people about needle hygiene. More on this and other federal issues next time.

Hot Briefs
by Richard Uhsmann & Mic Sweney

New York, N.Y. An ad hoc committee of ACT UP/NY has recently formed Art+, in response to "rising art star" Mark Kostabi's anti-PWA statements as: "These museum curators, that are for the most part homosexual, have controlled the art world in the eighties. Now they're all dying of AIDS and although I think it's sad, I know it's for the better. Because homosexual men are not actively participating in the perpetuation of human life" (Vanity Fair, 6-89). Art+ held that Kostabi is an unusually blatant voice for feelings more veiled in the larger art community.

Lansing, Mich. The Michigan legislature has recently approved an innovative plan whereby the state will cover health insurance premiums for PWA's. While medical expenses paid through federal and state Medicaid programs average $1600 per person per month, private insurance premiums are only $250 per person per month, which is still beyond the reach of many PWAs.

New York, N.Y. Over Gay Pride Weekend, the Radical Faeries, joined by ACT UP/NY, reenacted the Stonewall rebellion. On Friday night they began with a mock funeral for Judy Garland (whose funeral was the same day as the original Stonewall rebellion). While pallbearers bore a casket blaring out Garland tunes, hundreds of "mourners" sobbed at the side. On Saturday evening, the actual Stonewall riot was reenacted. As the numbers grew, some people began demanding answers regarding the recent murder/mutilation deaths of 2 black gay men on NYC piers. Calls came to march on the Sixth Precinct station house near Sheridan Square. At the Sixth Precinct, the crowd quickly blockaded the front. An American flag was burned while demonstrators chanted and the police stood by silently.

Austin TX. Faced with cowboys and bible thumpers, AIDS activists in Texas are thinking big and creatively. ACT UP/Austin has staged a guerrilla theater carnival (with a budget cutting booth, and a throw a red-colored water filled condom at an activist). Other actions have included dressing in black, wearing skulls and handing out flyers. They have also staged a mock crucifixion.
July

20 Jewish Film Festival at Castro Theater and UC Theater through August 3.

27 ACT UP Forum: "AIDS in the Latino Community"; 7:30 pm, MCC, 150 Eureka St

20-25 Anarchist Conference and Festival, "Without Borders," no charge, but donations accepted. Horace Mann Middle School, Valencia & 23rd St. For info call 861-7609 or write 1369 Haight St. Workshops on AIDS activism, lesbian & gay issues among others.


22 10th Anniversary of the Nicaraguan Revolution.


23 AIDS walk begins 9 am at bandstand in Golden Gate Park. Benefits a variety of AIDS organizations. Call 896-WALK.

23 Poetry Reading Benefit for "Living Word Memorial," anthology of work by poets who have died of AIDS. Bring written pieces and money. Paradise Lounge, 1501 Folsom (at 11th), 8 pm.

30 "Environmental Illness and Occupational Health Issues," Lesbian Health Forum, 2-5 pm, Morrissey Hall, 2200 Hayes St., $5 donation. No scents or perfumes. Wheelchair accessible. Info 261-1971 or 626-7000.

Some guys with some shirts at some demo.

August

31 ACT UP forum: INS and HIV. 7:30 pm, 150 Eureka.

ACT UP in Montreal

by Sean McShee

Several ACT UP/SF people went to Montreal for the simultaneous 5th International AIDS Conference and the ACT NOW Steering Committee Meeting. Activists significantly changed the terms of the conference through frequent direct actions and confrontation.

ACT NOW Regional Rep Mike Shriver said of the actions: "Montreal broke open the door that the action on the Golden Gate Bridge demonstrated was possible to break through ... that anger, directed at the forces which are responsible ... is one of our most effective tools. Activism is a tool that not only empowers us, it also informs everyone ... Not only are we a force to be reckoned with, we continue to be a force that must be answered."

The ACT NOW Steering Committee is a loose network of AIDS activists groups (and some direct action lesbian/gay groups) from across the country. New York ACT UP is not a member but sent observers. The major decision was to remain a loose knit network and not a centralized decision making body. This thorny question will not be taken up for a full year. Several proposals for joint actions were circulated and sent back to local groups for final approval: an October action in DC aimed at Congress, an April action in Chicago aimed at insurance companies, and a June teach-in in San Francisco just prior to the 6th AIDS Conference and Lesbian/Gay Week.

Keep ACT UP, Acting Up

Here's some money, keep up the fight!
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Put me on the Newsletter mailing list
Put me on the phone tree for upcoming actions

Mail to ACT UP/SF 2300 Market Stree Suite 68, San Francisco, CA 94117

ACT UP/SF meets Thursday nights, 7:30 p.m. at 150 Eureka Street. Everyone is welcome.

ACT UP/SF July-August '89
Goodbye Ronbo, Hello Ronbo II

If Bush wishes to stress the continuity of his administration with that of his not so illustrious predecessor, so be it. Many of us in ACT UP/SF intend to stress the continuity of our opposition and resistance. Rather than a presidential honeymoon, let's have a divorce with full alimony payments.

Bush Counter-Inauguration

Friday, January 20, 1989 8:00 a.m.
ARC/AIDS Vigil U.N. Plaza,
7th & Market Rally and march
to the Pacific Stock Exchange
301 Pine Street

From a compassionate government, the response to AIDS would be swift, complete, and caring. But under eight years of Reagan we have seen ignorance, homophobia, and encouragement of AIDS profiteering. Companies like Burroughs-Wellcome (AZT) and Lyphomed (aerosol pentamidine) are reaping windfall profits while keeping their drugs out of reach of PWAs and bankrupting many others. Health care in this country is still viewed as means toward profit rather than a right. (Of the advanced industrial countries only the US and South Africa do not guarantee health care).

We plan to acknowledge the change of administrations by marching from UN Plaza to the Pacific Stock Exchange. UN Plaza is the site of the oldest, most continuous ARC/AIDS protest in the world. The stock market is where people with money (PWMs) spend their days gambling their money and gambling with our lives. Speakers and scenarios for the demonstrations are still being arranged. Expect colorful ACT UP-style street theater and the possibility of civil disobedience. (See CD Training information elsewhere in this issue.).

While many are despondent about the coming Bush regime, ACT UP/SF plans to make inauguration day just the next (noisy, spirited, empowering) step in seizing control of our government and our lives. Join us!

Act Up, Set Type, Fight AIDS!!

Welcome to the first edition of the new ACT UP/SF newsletter. The newsletter will help you keep up on what we’ve been doing and help you plan for the actions you’d like to be involved in.

We welcome written contributions to the newsletter and feedback on what you’ve read.

The Education Committee on Thursday, January 26 will discuss submission and editorial policy.

Please see the next page for more information on how to continue receiving this newsletter.
Our Goals and Demands

ACT UP (the AIDS Coalition to Unleash Power) is a nonpartisan group of diverse individuals united in anger and hope. We are committed to direct action to end the AIDS crisis. We demand massive governmental funding for research, health care, education, anonymous testing, and treatment. The research for treatments, vaccines, and cures should be centrally coordinated and publicly accountable to the communities most affected. We demand free nationalized health care guaranteeing equal access, regardless of ability to pay. We demand a federally-funded sex positive education program to promote safer sex. We demand that information on needle hygiene be made available to all needle users. We further demand that addiction treatment/recovery programs be expanded and available to all regardless of ability to pay. We further demand that these programs be instituted in a culturally sensitive international program.

ACT UP/San Francisco grew out of the AIDS Action Pledge, implemented in 1987 to respond to the deplorable government and private sector response to this crisis. We're part of a growing worldwide movement, coordinated nationally through ACT NOW (AIDS Coalition to Network, Organize, and Win).

How To Get This Newsletter

The money for this newsletter comes from the ACT-UP general fund. This newsletter costs approximately $.50 per issue. We understand that not everyone who needs/wants this newsletter can afford it. Therefore, we are not charging a subscription rate. But if you can, please send us the money to cover your issues and that of someone who can’t afford it. And if you want to make a contribution, please do so.

We estimate that 25% or more of our addresses are no longer valid. Therefore to cut costs we ask that you fill out this subscription coupon and return it to us (either at the General Meeting, at our table or in the mail.) IF WE DO NOT HEAR FROM YOU, YOU WILL NO LONGER RECEIVE A NEWSLETTER.

ACT-UP events hot line 563-0724.

ACT UP
SAN FRANCISCO
AIDS COALITION TO UNLEASH POWER
VOLUME 1 NUMBER 1 JANUARY 1989

The ACT UP/SF newsletter is published by the Education Committee of ACT UP/SF. At the moment, the Education Committee consists of Maria, Ed, Sean, Richard, Danny, and Eric. Articles appearing here do not necessarily represent the viewpoints of all those involved with ACT UP/SF.

Letters and material appropriate for publication may be submitted to:

ACT UP/SF
Education Committee
P.O. Box 460693
San Francisco, CA 94114

Send a photocopy, not the original.
For additional information on ACT UP/SF events call the Hot Line at 563-0724.

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WHERE WE'VE BEEN: WHAT WE'VE DONE

From the FDA to NBC

ACT UP/SF has been involved in many exciting and effective actions in the past few months.

Return to Washington One year after the 1987 March on Washington activists returned to Washington for a weekend long conference of AIDS activists, a rally at the Department of Health & Human Services, and a massive civil disobedience at the Food & Drug Administration.

The CD showed we are truly united in our goal to seize control of our lives and the epidemic and that we love to ACT UP.

The conference featured workshops like Art and AIDS Activism, and Pushing the Limits of Legal Protest. We had a chance to talk with people from all over the country doing the same kind of work we are.

Several thousand AIDS activists shut down the FDA in high spirited, energetic and creative civil disobedience. Several ACT UP/SF affinity groups had a high profile: PISD (People With Immune System Disorder) Caucus, Forget Me Nots, Formica Fag, and Purple Rage. PISD members sounded a siren each half hour providing a piercing reminder of one AIDS death every 30 minutes. Purple Rage hung several banners, occupied rooftops, and changed a drug store sign (Rite Aid) spelling out “Fight Aids.”

The CD provided a great opportunity to work with and form bonds with people from different cities. Though the weekend conferences seemed at times fraught with controversy and contention, the CD showed we are truly united in our goal to seize control of our lives and the epidemic, and that we love to ACT UP!

No on 96 & 102 When it became clear that the established gay political community would do nothing to fight L.A. Sheriff Sherman Block’s Proposition 96, ACT UP/SF members were instrumental in starting a small but rowdy Bay Area No on 96/102 group. The group organized leafletting, marches, rallies, speakers’ appearances, postering and editorials. In the end, Prop 96 passed statewide but San Francisco voters rejected both measures.

Election Action ACT UP/SF was involved in several election protests this fall. Probably the biggest and loudest was the anti-Bush rally at the Fairmont Hotel on September 14. ACT UP/SF helped show George one of the many cities he’s not welcome in.

ACT UP/SF put together a boisterous election night rally and march. Over 2000 people gathered to celebrate our victories and to show we’re not going to take the coming Bush era quietly. Around midnight the rally became a loud, feisty march through the streets stopping at the State Building and Republican Headquarters.

Over 2000 people gathered... to show we’re not going to take the coming Bush era quietly.

Midnight Caller See article elsewhere in this issue.

ACT UP/SF contingents were also present at the United Farm Workers March, at the Milk/Moscone March on Sunday, Nov. 27 and working against Operation Rescue’s abortion clinic attacks. (Please see the calendar for more Operation Rescue details).

Lot’s of inspiring actions are planned for the coming months. Check the upcoming events schedule elsewhere in this issue.
HOW WE WORK:
Structure and Committees

In addition to the general Thursday night meeting, ACT-UP has 5 working committees, 2 caucuses, a secretary, a treasurer, and a representative to ACT-NOW (AIDS Coalition to Network, Organize and Win, a network of US AIDS Activists). Each working committee and caucus selects a rep. The 5 committees and 2 caucuses together with the secretary and treasurer and the ACT-NOW rep form the Coordinating Committee. All committee meetings, including the Coordinating Committee, are open.

Most of the actual work gets done in the committees, and every committee is in need of more members. So if the Thursday night meeting is not for you you might want to check out these working committees. Since the time and place of these meetings vary, call the rep listed below if you are interested.

As of January the Thursday night general meetings has changed schedule. On the second and fourth Thursday of the month the last part of the meeting will be mini-committee meetings. This is yet another way you could check out the committees. See the calendar section of this newsletter for more details on the new schedule.

As of December 1, 1988 the new Coordinating Committee members are as follows.

**Outreach:**
Rick Jacobsen 552-1775
Tabling, leaflet distribution, the phone tree and coalition work.

**Caucuses**

PISD
(People with Immune System Disorders)
Bridget Lawthor 552-6918
& Waiyde Palmer 861-2738
People with AB+, ARC, AIDS, Epstein-Barr Virus, Chronic Viral Fatigue Syndrome, etc.

**Women’s Caucus**
Kelly Gaines 282-0859
Development of women’s perspectives and issues on HIV and other immune disorders.

**Specific Roles**

ACT NOW Rep:
Arawn Eibshly 863-5770

Mike Shriver 863-0931
Secretary

Jean-Jacques Zenger 673-2323
Treasurer

All of the above form the Coordinating Committee. The Coordinating Committee sets the agenda for the Thursday meeting, coordinates the various committees and makes some emergency decisions.

*This structure is flexible. There is space for, and a commitment to, a People of Color caucus. Terry Sutton (621-7996) has been trying to organize a Treatment issues committee. Give him a call if you would like to work on that committee. So if you have an idea for a committee either come to the general meeting or contact a member of the Coordinating Committee.*
Midnight Calls Forth Anger

The first TV series to be filmed in the city since "The Streets of San Francisco" has arrived. The city can now claim as its own, Midnight Caller, produced by Lorimar Productions the same company that brought you "Cruising."

Last September, a Lorimar employee happened to read the script of an episode titled "After It Happened." The employee, shocked at the inflammatory, inaccurate, and insensitive nature of the story, contacted ACT UP. It became clear there were two major problems with the script: 1. The episode's main character, a bisexual man, was knowingly and maliciously spreading HIV through unprotected sex, and 2. The climactic scene included the vigilante-style murder of this character by an infected female partner.

Soon ACT UP, Mobilization Against AIDS and the San Francisco AIDS Foundation, working through the Mayor's office, confronted Lorimar with their concerns. Members pointed out the factual errors and the real possibility of more violent attacks against PWAs after the airing of such a program. The meeting failed to get any concessions on the script.

At the next ACT UP Thursday night meeting it was announced that Lorimar was filming the final murder scene at that very moment. As the meeting's agenda turned from processing to protesting, 75 people caravanned to Jones & Broadway and shut down production for the evening. Soon after, Lorimar successfully obtained a Temporary Restraining Order (TRO) against ACT UP protesters. The following Tuesday over 300 protesters again shut down Lorimar's production. This time the at the South of Market bar, Lipps.

The next protest was directed at KRON, the local NBC affiliate scheduled to air the Midnight Caller series. ACT UP and GLAD (Gays and Lesbians Against Defamation) organized a march of approximately 100 people from the Castro to KRON on Van Ness. KRON later decided to air the episode with a disclaimer preceding the show and a half hour discussion program following it.

On Tuesday December 6, ACT UP organized a protest at San Francisco Studios, the facility used for all interior filming of the series. An orderly but vocal picket line shut down the facility for over an hour. And on the evening of the premiere, our actions climaxed in a massive protest, again at KRON. Over 200 people screamed, circled, and occupied the KRON entrance. Vigil candles, blood red handprints, floodlit banners reading "KRON: This is what friends are for?" - creating a visual tapestry in which 10 activists were arrested. Call the Events Line for information on their trial:563-0724.

The final version of "After It Happened" which aired December 13 still focused on a character knowingly spreading HIV. ACT UP and other groups were able to get the ending changed to only an attempted murder (she misses) and to get some changes in dialogue. More importantly, ACT UP demonstrated that the people of San Francisco will not be host to irresponsible, AIDSphobic television.

Do I have to train to get arrested?

Civil Disobedience (CD) is an emotional and political process. These trainings provide a space to explore both the reasons and the feelings of CD.

CD trainings are not lectures, they involve role playing and other small group processes. Trainings help you understand the legal system, affinity group structure, non-violent direct action guidelines and the philosophy of CD. You may even form your own affinity group through the training.

The next CD training will be held January 15 at 11 am at 347 Dolores, #315. If you think you might want to be part of the January CD training, call 864-1988 to register.
Events for Days (and Nights)

ACT UP events are underlined

Jan 12 - ACT-UP General Meeting 7:30 pm. Committee Meetings 8:45, 150 Eureka.


Jan 14 - Operation Rescue strikes again. Call Bay Area Coalition Against Operation Rescue (BACAOR) at 824-8562 for abortion clinic defense strategy and information.

Jan. 14 - Nazi Skinhead Recruiting Rally in Rocklin, CA. For information on the counter-demonstration, call John Brown Anti-Klan Network at (415) 330-5363. To protest this Nazi recruitment call the Mayor of Rocklin (916) 624-3351.

Jan 15 - Civil Disobedience (CD) preparation for ACT-UP counter-inaugural. At 347 Dolores #315, 11:00 - 6:00.

Jan. 16 - Holiday - Martin Luther King Day.

Jan. 19 - ACT-UP Full general meeting. 7:30 pm, 150 Eureka.

Jan. 20 - ACT-UP Counter-Inaugural 8 am at UN Plaza. March to Pacific Stock Exchange.

Jan. 20 - All People’s Congress/Coalition Counter-Inaugural. Call 821-6545 for more information. (These two counter-inaugurals are not in conflict. You can go to both.)

Jan. 26 - ACT-UP Educational Meeting “Abortion, Reproduction Rights & AIDS” 7:30, 150 Eureka. 8:45 pm committee meetings.

Jan. 31 - Introductory Workshop in Tax Resistance. 7:00 pm, 347 Dolores, Rm 228, by California War Tax Resistance, for people concerned about AIDS issues. Sliding Scale. For information call 548-7059.

Feb. 2 - ACT-UP Full General Meeting 7:30, 150 Eureka.

Feb. 9 - ACT-UP General Meeting 7:30, Committee Meetings 8:45, 150 Eureka.

Feb. 16 - ACT-UP Full General Meeting 7:30, 150 Eureka.

Feb 18/19 - State-wide meeting of California Direct Action Network (C-DAN) at 333 Valencia, 4th Floor. A state-wide organization of lesbian/gay activists committed to direct action. Feb 18 from 11 am to 5 pm. Feb 19 from 11 am to 3 pm. Call Arawn (863-5770) for more information.

Feb. 23 - ACT-UP educational forum topic to be announced (call 563-0724) 7:30. Committee meetings 8:45, 150 Eureka.

Apr. 5-9 - 11th National Lesbian and Gay Health Conference, Cathedral Hill Hotel, San Francisco, CA. At present there is no local number. Call (202) 994-4285.

If you have an event you would like listed in our ACT-UP calendar, please send the information to ACT-UP/SF Newsletter, PO Box 460693, San Francisco, CA 94114.
ACTIONS AROUND

HOT STUFF

Boston, MA: December 19, over 200 people joined Boston ACT-UP outside the headquarters of insurance giant John Hancock in protest of its policy not to pay for aerosol pentamidine. There were several arrests.

Cleveland, OH: After the Mayor of Cleveland denied funding for an AIDS Community Center, ACT-UP Cleveland held a militant protest in downtown Cleveland. The Lesbian/Gay Student Union of Oberlin College was the main force behind the founding of ACT-UP Cleveland.

Los Angeles, CA: There are no wards in the LA County Hospital system dedicated to the treatment of ARC/AIDS. On December 15, a coalition of People of Color AIDS organizations and ACT-UP LA demanded that such wards be created. Mark Kostopoulos of ACT-UP LA has called for a seven day vigil beginning January 21, at LA county to keep the pressure up.

Portland, OR: ACT-UP Portland negotiated with the local NBC affiliate concerning Midnight Caller. After several and duplicitous negotiations, they held a sit-in. Four people were arrested.

Seattle, WA: In what may be a first, ACT-UP Seattle has formed with a lesbian majority.

Portland, OR: December 1, Richard Carpar a PWA, and a recovering intravenous drug user (IVDU), began a hunger strike to demand that the Federal Government take AIDS seriously. He ended his hunger strike December 8 after receiving a letter from Bush pledging to take AIDS seriously and supporting anti-discrimination legislation.

Workshop on Racism

On December 3, Penn Garvin facilitated a workshop entitled “Unlearning Internal Biases”. A dozen of us explored ways that racism affects us and our organizations. We want to use what we learned to make ACT UP a group where people who are “different” feel included and able to contribute. We learned how someone in the majority group can become an “ally” and we came to see that the “in-group” can unintentionally keep people out.

We asked the Education Committee to do more internal education on minority issues and on group process to make ACT UP meetings “safe” for everyone. We asked the Outreach committee to go to lesbian/gay and AIDS people of color organizations. And we have started a discussion/support group to work on minority issues. (Call Ed at 864-1988 about this racism/minority issues group).
Why No Antivirals: A Case History of Failed Trial Design

by John S. James

AZT provides limited benefits to persons with AIDS or HIV, and many people cannot use it at all. Many promising new antivirals have long been in the research and regulatory pipeline: for example, DDI, AZDU (CS-87), D4T, DDC, hypericin, and trichosanthin (compound Q). None has become available since AZT was released almost three years ago. And at the Montreal AIDS conference earlier this month, we learned why none will become available for years—unless certain current practices in the design of clinical trials can be changed. This article will illustrate some of the problems, and suggest solutions.

The basic problem lies not in any single agency, company, or other institution, but instead in a conventional wisdom which cuts across institutional boundaries. A professional consensus guides the design and conduct of clinical trials, and the shepherding of experimental drugs through the testing system. This consensus today includes certain assumptions which make it impossible for the existing system of clinical trials and drug approval to respond successfully to AIDS as a public-health emergency.

Note and disclaimer: Readers may notice that this issue of AIDS Treatment News has a call for volunteers (above) for the same trial analyzed below as an illustration of a failure of the clinical-trial system. This is not an oversight or contradiction.

This trial is no worse than other AIDS studies. It seems to be ethical in its treatment of volunteers. The problem is that it will not produce results for years. But for now it is the trial we have, so we must support it.

For the same reason, this article is not intended as a criticism of persons conducting this trial, nor of its sponsor. They have done well within the system of shared assumptions which controls all mainstream AIDS research. It is this system which needs reform.

A Case History: New DDC Trial

DDC (dideoxycytidine), an antiviral like AZT but with different toxicities, is not the most important new drug. But it is farthest ahead in the drug-approval pipeline among major antivirals. Because it is ahead of the others, and plans for a major new study have been revealed, it provides an excellent case study of the problems which will impede the approval of all important new antivirals, not only DDC but also more interesting drugs such as DDI.

DDC Background

DDC, like most of the new AIDS antivirals, was discovered to have anti-HIV activity by U.S. Government scientists. The United States then asserted exclusive worldwide rights, and assigned these rights to a pharmaceutical company (in this case, Hoffmann-La Roche, Inc. of Nutley, New Jersey). Several trials have already been conducted. In early studies, some patients developed severe peripheral neuropathy, causing numbness or pain in the feet. Later human studies found that lower doses could reduce P24 antigen levels, a sign of antiviral activity, with manageable toxicity.

On June 5, 1989, Hoffmann-La Roche announced new trials, designed in cooperation with the FDA (U.S. Food and Drug Administration). A major phase II trial, which could lead to marketing approval for the drug, will compare low-dose DDC head-to-head with AZT “in persons with AIDS or advanced ARC.”

The problem with this trial is that because of the design chosen, it is unlikely to produce any conclusion for two and a half years.

And since DDC is ahead of all other major antivirals in the drug-approval pipeline, and the delays in this study design are generic to AIDS antivirals and not specific to DDC, it is likely that all major new AIDS drugs will face a similar delay. This fact alone strongly suggests that no major new treatment for AIDS will come out of the drug-approval pipeline for years, unless the assumptions currently guiding clinical trials can be changed.

An analysis of the design of the new DDC/AZT comparison trial, and the assumptions behind this design, will show exactly how this intolerable situation came about, and how it can be changed.

DDC Rumor: A Treatment IND?

Rumors have circulated that DDC may become more available through a “treatment IND” before the end of 1989. We hope these rumors are true.

But we are skeptical. The FDA has interpreted the treatment IND very conservatively, using it only near the end of efficacy trials, when the drug is almost sure to get full marketing approval after the final paperwork is complete. If this procedure is followed for DDC, a treatment IND will probably be more than two years away, as we will show below.

The record is full of comforting but broken promises that things have changed and therefore AIDS research will move faster in the future. When the future arrives, the public has forgotten the promises.

Why will the trial take so long?

This new phase II trial will compare DDC with AZT, using a randomized, double-blind design. No placebo will be used; every patient will get one of the drugs. The trial is scheduled to last two years; recruiting the subjects is expected to take about six months in addition.

In theory, the study could end earlier. A team of experts will periodically monitor the results, secretly breaking the code to see if there is statistical proof that patients getting DDC are doing much better or much worse than those getting AZT. In practice, however, for reasons explained below, it is almost impossible that this study will end this way. The researchers expect it to take the whole two years.

The reason that the study will take so long must be explained in several steps:
(1) The FDA will not approve a drug based only on “surrogate markers,” meaning improvement in blood work such as reduction in P24 antigen, or T-cell rises. The FDA also wants statistical proof that the drug is helping people.

(2) After rejecting surrogate markers, the FDA has insisted on the slowest measure of clinical improvement—“clinical endpoints,” meaning OIs (opportunistic infections) or deaths. This means that the drug being tested is not measured by improvements in the patients who receive it, but OIs or deaths in those who do not.

The DDC trial will compare that drug with AZT. Since AZT works fairly well for the first year, the number of deaths and OIs in the control (AZT) group will be low. Therefore, even if the drug being tested were perfect and everybody taking it were cured instantly, the clinical trial design would not recognize that fact until enough deaths and OIs had accumulated in the control group to provide statistical proof that DDC was no worse than AZT.

(3) This study, like some others, will use a team of experts (sometimes called a “data safety monitoring board”) to meet periodically and secretly break the code and examine the results so far, to see if the study should be ended early. The public is told that such reviews can end studies as soon as statistical proof of effectiveness is obtained.

But in practice it is unlikely that this or any similar study will be ended early. The reason why not involves an esoteric problem in statistical interpretation. If researchers take an early look at their data to decide whether to stop the study early and call the drug a success, but then decide that the data does not justify stopping, meaning that the study will run to its normal conclusion, then the very fact that they looked early means that they must tighten their interpretation of the final results. A drug which otherwise could have been considered a success might now need to be counted a failure—just because the researchers looked at the data and might have acted on that information—even though in fact they did nothing different as a result of the look.

This seemingly preposterous conclusion is hard to explain even to scientists, let alone to readers with no statistical background. We will try to do so; those who are not interested in the details can skip the next four paragraphs.

[When researchers claim statistical proof that their drug works, they are usually claiming that the drug passed a test which only a small percentage of worthless drugs could have passed by chance; the smaller the percentage, the better. For example, if a journal article claims that a result is “statistically significant at the p<0.01 level,” this means that the probability (p) that a worthless drug could have done as well or better by chance alone is less than one percent (0.01).

What happens, then, if you look at the data early? Suppose that the researchers did not know about the problem that we are describing here, and they decided to take an early look at their data, and end the trial immediately if the drug was good enough to have reached the p<0.01 level already. If not, they would continue the study and see if they achieved that level later.

Clearly then the chance of accepting a worthless drug at some time in their trial would now be greater than one percent. This is because there is a full one percent chance to accept such a drug at the early look—and if the worthless drug did not pass the test at that time, there is some additional chance that it could pass later. Since the overall probability of accepting a worthless drug is now greater than one percent, the researchers cannot correctly claim that their trial showed efficacy at the p<0.01 level. To honestly make that claim, the researcher must use a higher standard both for the early look, and also at the normal end of the study (if the early look did not result in the trial’s termination).

This means that if researchers take an early look at their data but decide not to end the study as a result, they then must tighten their standard for judging a drug successful later. Drugs which would otherwise have been judged effective will therefore now be rejected. Clinical trial design can minimize this problem by making the early look be as conservative as possible.]

The practical effect of this statistical oddity is that researchers have a strong incentive to use an extremely conservative criterion for ending a study early. As a result, a “data safety monitoring board” provides less protection to the volunteers in a study than they may be led to believe. And the assurance to the public that experts are monitoring the trial and will end it as soon as the data justifies, thereby speeding final approval of the drug, is largely empty.

(Note: The AZT trial was stopped early in September, 1986, when there were 16 deaths in the placebo group, vs. only one death in the AZT group. No one knows why this extreme difference occurred, as later experience does not support a 16 to one difference in death rate with AZT. And despite this great difference in deaths, the decision to stop the study then has been controversial.)

During the Montreal conference, Hoffmann-La Roche conducted a press conference on DDC. The speakers were Thomas Merigan, M.D., principal investigator at the AIDS Clinical Trial Group at Stanford University, and Whajen Soo, M.D., Ph.D., director of clinical virology at Roche. Few reporters came to this meeting, which was a mile away from the main conference. Our impression from the discussions at that press conference is that nobody expected the study to end before two years.

The important question is not whether to end studies early. It is whether the best way to prove a drug is to wait for deaths and OIs in those who do not receive it. This trial design makes studies inherently slow, whether they are ended early or not.

No one at the press conference raised the issue of whether a study design which will take more than two years to get results is an acceptable public health response to the epidemic. We are concerned that all the important AIDS antivirals are behind DDC in the pipeline. If they suffer the same delay as DDC, then we can almost guarantee that no major new AIDS antiviral will be generally available for at least two years.

Recruiting Problems Likely?

One of the problems with many AIDS clinical trials is that entry criteria are designed purely for scientific reasons, without thought as to whether there will be patients available to fit them. As a result, many studies take much longer than intended, or even fail altogether, because of recruiting difficulties.

The DDC study may have this problem. Volunteers must have less than 200 T-helper cells, and also have had pneumocystis in the last four months or have certain ARC symptoms. And yet they must have never taken AZT. Most people will have already tried AZT before they have severe symptoms and under 200 T-helper cells.

Some may have never taken AZT because they chose not to. But they would be unlikely to volunteer for this study—because 50 percent of the people enrolled, chosen at random, will go into a control group and receive AZT instead of DDC.

It seems that the only volunteers left would be those who never took AZT because they could not afford it; in the study, the drug is free. But these people face another problem. The study also requires use of aerosol pentamidine, but will not pay for it. If persons could not obtain
The Ideology and Public Relations of Clinical Trials

Having looked at the reality of the modern phase II clinical trial for AIDS antivirals, we will now look at the image. The image is important, because it is used to calm the public, justify the existing system, and impede calls for reform.

The DDC press packet from Hoffmann-La Roche provides a convenient look at this image. Any other public relations from a mainstream clinical trial would be similar, however, as government and other controls have imposed a research monoculture. Even the public front is uniform.

From a June 5 press release we learn that “Everyone collaborating on this project at Roche, the FDA and the National Institutes of Health is intensely aware of the urgency for developing safe and effective treatments for AIDS. Awareness of that urgency constantly compels us to work together as expeditiously as possible toward definitive results.” We also learn that “Initial studies suggest that DDC may have an antiviral effect at the low doses that result in manageable toxicity. The studies now being planned are essential if we are to turn suggestions into medically useful conclusions.”

An undated Dideoxycytidine (DDC) Fact Sheet includes a question and answer section on the availability of DDC. We quote it at length because it illustrates several aspects of the currently prevailing ideology of clinical trials.

“Q: When will DDC be available?

“A: That depends largely on the results of the new trials. When dealing with human life, the adverse effects profile and optimum dosage of a drug must be carefully studied no matter how urgent the need. As soon as the clinical data warrant, Roche will file a New Drug Application (NDA).

“Meanwhile, each of the new trials has entry criteria specific to its design, and some of the studies already have their full complement of volunteer patients. People who would like to participate in, or simply learn more about, the trials should call FDA (sic) at 800/874-2572 (800/TRIALS-A) or Roche (collect) at 201/235-2355.

“Q: Will Roche provide DDC on a compassionate plea basis?

“A: The urgent need for more effective weapons against HIV weighs heavily on everyone associated with this project at Roche, the FDA, and the NIH. However, at present, we are agreed that the clinical data now available are insufficient to justify distribution or use of DDC against AIDS outside of carefully controlled clinical trials. Only new data can change this situation. Consequently, we are working closely together to expedite the next round of therapeutic trials, from which the medically necessary data will flow.

“Q: When will Roche submit an NDA for DDC?

“A: Roche will submit an NDA as soon as the data from the pivotal studies allow. A special review board will continually evaluate data from all of the trials and make appropriate recommendations to FDA.”

Some points to note about the world of AIDS treatment research according to press releases:

(1) Everyone involved feels urgency, and is working well with everyone else. (During the press conference, however, this reporter could find no shred of evidence of urgency.)

(2) More studies are, of course, essential. (300 people have already been given DDC in clinical trials.)

(3) The phrase “no matter how urgent the need”, in the context of justifying withholding a drug until more studies collect still more information about “the adverse effects profile and optimum dosage”, clearly illustrates the fact that no weighing of costs and benefits (of the extra studies and their associated delays) will be considered. Instead, persons with AIDS can simply get lost until the researchers are finished. In theory they might join the study, but in practice less than one percent of persons with AIDS or related conditions will be able to do so.

Incidentally, the dose has already been determined well enough to bet this entire phase II study on it, as only one dose will be used in this study.

(4) Unless they qualify for a trial, patients and their physicians have no role in the decision of whether or not to use a drug, until someone is ready to sell it to them. This decision is made for them, by agreement between government officials and potential vendors. For AIDS, the answer is almost always no. Other diseases have been treated more liberally.

(5) The public is not told that the reason the trial will take so long is that deaths and OIs must be accumulated. Instead, the public is told that the trial might not take two years but could end any time, because experts will watch over it and pull the plug as soon as medically possible, moving the drug to the next step in the approval pipeline. As we have seen, this study will almost certainly take more than two years.

(6) The Dideoxycytidine (DDC) Fact Sheet also said that the first comparison trial was expected to “begin” in July and last up to two years, “depending on results”. Readers might assume that the maximum delay for this trial is therefore two years and one month. This assumption would be wrong.

The six months for recruiting subjects was an informal estimate mentioned by one of the researchers at the press conference. Past experience suggests that it is probably optimistic.

Note that a trial which “begins” in one month and lasts “up to” two years may take far longer than 25 months to be finished. This is because the trial “begins” with the recruitment of the first subject, but the two-year clock starts only with the recruitment of the last. In addition, multicenter trials often have recruitment quotas for different centers, meaning that the clock starts only when the slowest center is ready.
The difference recruitment can make is illustrated by a study of Imuthiol (DTC). Over two years ago, on April 10, 1987, AIDS Treatment News reported that this six-month study was underway. Most centers recruited patients promptly and completed their phase of the study. But because of stragglers, this six-month study was still running two years later, and the data from those subjects who completed the trial long ago has not been released.

The point is that press releases about clinical trials are designed to provide a comforting picture of reality. Since clinical research is a forbidding area—complex, esoteric, and involving risk to human life—few in the media or elsewhere have looked behind the image. It is much easier to trust the experts.

Because of lack of understanding of what is really going on, people are repeatedly surprised at the lack of new drugs for AIDS. Those who do look will realize that the current system of clinical trials could not possibly meet the needs of the AIDS emergency, and is very unlikely to release even a single important new AIDS drug for years—even though the drugs are there. The drugs which will provide the important treatment advances of 1992 and 1993 are already available and quite well known—we named some of them above. But DTC will take over two years for the upcoming trial alone, and all the other important antivirals are behind it in the pipeline, so they will take longer still.

The Central Issue

The key reason no new antivirals are available is that clinical trials have waited for deaths and OIs, instead of looking directly at clinical benefit, which with some drugs is dramatic. Conservative trial designers have used deaths and OIs because the numbers seem more "scientific" than clinical ratings, which depend in part on judgments of physicians, and may not be identical from one researcher to the next; by contrast, everyone can agree precisely on the number of deaths in the treatment and control groups. However, "softer" kinds of data such as average ratings by panels of experts have been handled successfully in many fields of science. When we are looking for dramatic effects, as with DDI or Compound Q, these methods have more than enough precision to do the job.

The AIDS community must continue to raise the issue of whether counting deaths and OIs is truly the only legitimate way to tell whether an AIDS antiviral is working. Using "surrogate markers", such as T-helper cell count or P24 antigen level, is one approach to faster study design.

But we fear that surrogate markers alone are not enough—that to try to use blood work as the sole basis for approving new drugs would lead to a long and unproductive argument. A middle ground, which we believe will be most productive, is to use surrogate markers and also direct measurements of clinical benefit in persons taking the drug, such as numerical ratings based on examinations by physicians. The variability in the course of the disease, sometimes cited in arguing against this approach, can be controlled for by double-blind designs, and by well-known statistical methods. The purpose here is to find the dramatically effective drugs, the home runs, and to test them quickly; slower study designs are acceptable when researchers are looking for minor or marginal differences.

The issue of surrogate markers is already receiving serious professional attention. But the related issue of the reluctance of trial designers to use direct measures of clinical benefit as proof of efficacy of AIDS antivirals, instead of insisting on deaths and OIs in the control group as the only important measure, has been largely overlooked. The AIDS community must insist that this issue be considered on its merits, as this key reform will allow the most important new AIDS antivirals to be tested many times faster than by the methods now in use.
During the usual preliminary announcements of our meeting, anticipation grew as to what action we would take in response to this blatant disregard of accepted public health policy. It was announced there was a live phone hookup to our fellow Act Upers in Montreal. The facilitators moved the agenda to Zap proposals. When it was discovered no

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ACT UP

This is the newsletter of ACT UP New York.

ACT UP is a diverse, non-partisan group united in anger and committed to direct action to end the AIDS crisis. We protest and demonstrate, we meet with government and public health officials, we research and distribute the latest medical information, and we are not silent.

Everyone is welcome to join our meetings and our actions. Meetings are every Monday evening at 7:30, at the Lesbian and Gay Community Services Center, 208 West 13 Street, NYC.

ACT UP 696 A Hudson Street, Suite G4, NYC 10014 (212) 553-9888

All contributions to this issue reflect the opinions and perspectives of the authors and are not necessarily the consensus of ACT Up as a whole.

We dedicate this issue of our newsletter to Steve Zabel, a model of journalism at its finest, a walking paragon of the First Amendment. He was dedicated with every fiber of his being to telling the complete truth. He was one of the best anywhere. We loved him, we admired him and we miss him.

SCIENCE, RUMOR AND COMMODITY

A delay of 18 months anywhere in the treatment research and development process will account for half of the total deaths of the epidemic.

Incentives built into the system (are) to conceal an effective drug from the public; not to release it.

Large-scale clinical trials cannot be hidden, because too many patients are involved. Successful concealment is only possible at the early stages of a treatment's development...

The secrecy around the Compound Q research largely ended on the day the patent was issued.

—John James, AIDS Treatment News

"Patents are an important part of getting university innovations out to the public."

—Stephen Hurst

UCSF patent attorney

2 years and one month elapsed between Sam Broder's discovery that AZT was active in the test tube against HIV and its final approval by the FDA. It has taken just as long for GLQ223 (Compound Q) to get from the test tube to Phase I.

Whether or not the drug works in humans, this delay is criminal. It is an indictment not only of the sponsors, but of the dysfunctional approach of the entire US regulatory and corporate apparatus towards the AIDS pandemic. UCSF (the University of California, San Francisco) employs Michael McGrath, the man who discovered GLQ223's anti-HIV activity over 2 years ago, so UCSF holds the patents. GeneLab Inc. of Redwood City, CA, is the manufacturer. What were they doing for 2 years?: 1) confirming McGrath's initial findings; 2) conducting toxicity studies in mice, dogs and monkeys (humans have used the drug for centuries in China); 3) stockpiling 1.5 million doses of the drug for testing in humans; 4) negotiating a worldwide marketing deal with Swiss pharmaceutical giant Sandoz; and 5) waiting to receive their patent, which they got on January 3, 1989.

GLQ223 is trichosanthin, a purified protein derived from a Chinese cucumber root. It has been used for 1600 years in China to induce abortions. In 1986, a Hong Kong doctor, Kou Hwang, told McGrath of the protein's ability to induce abortion by selectively killing placental cells called trophoblasts, which closely resemble macrophages.

McGrath was looking for something that would kill all macrophages, but when he tested GLQ223 in lab dishes he found it killed only HIV-infected macrophages. While earlier HIV research focused on T4 cells, only 1 in 10,000

T4-cells are infected by HIV, though by some mechanism many others are killed off by the virus. 2%-7% of macrophages from HIV-infected persons are infected, according to McGrath. Macrophages function as search-and-destroy cells of the immune system, but when they are infected they become dysfunctional, surviving HIV infection only to serve as Trojan horses bursting with HIV, releasing doses of the virus into the bloodstream as many generations of T4-cells become infected and die.

A single dose of GLQ223 in HIV-infected macrophages stopped viral replication after 5 days and caused cell death after 21 days. Uninfected cells were not harmed by GLQ223. In contrast, an infected culture treated with AZT showed no change in viral activity, staying both infectious and alive. This result, derived from lab cultures, has given rise to speculation that a single dose of GLQ223 might kill all infected cells in an HIV-infected person. This is mere speculation and has no basis in fact. No results of testing in humans have been reported.

In addition to GeneLab's product, trichosanthin exists in several Chinese crystallized powder forms of varying degrees of purity. These powders may contain lectins, which can cause red blood cell clotting and are pyrogens, which can produce severe fevers, usually within 12 hours of injection. According to unconfirmed rumors, several people in Florida injected themselves with crystalline trichosanthin and experienced side effects. John James claims that "a standard chemical treatment called gel chromatography" can evaluate crystalline trichosanthin for impurities. One should experiment with such preparations without medical supervision.

If GLQ223 does (in humans what it does in the test tube, a number of possibilities remain open:

1) AZT stops viral replication at a relatively early stage in HIV's life cycle (when it writes itself onto host-cell DNA), so it doesn't affect already infected cells. GLQ223 might be 100 times more effective in killing most or all infected cells, and thus be far more effective.

2) If GLQ223 doesn't kill all infected cells, drug-resistant strains might develop. 3) It might wipe out HIV-infected cells but the immune system might not be able to regenerate itself after a certain degree of immune destruction has occurred. 4) It might destroy all HIV-infected cells but not alter the disease process, lending support to those who still claim HIV is not the cause. 5) Anti-abortion activists and racist homophobes might attempt to prevent the drug from being made available by charging an outrageous price (how much would you pay for a possibly one-shot drug that might save your life?)

Many obstacles to disband and reconstitute itself as the Argumentative Coalition to Unleash Polenick.

There will be many obstacles to finding out what we need to know fast enough. The first is the maddening lethargy of the drug establishment (convincingly outlined by John James in "The Drug Trials Debacle—Pt I, ATN 77). The second is the existing NIAID AIDS trials pipeline, clogged as it is with AZT. The third is the massive investment other pharmaceuticals have in competing products. The fourth is the hype generated by GLQ223 itself. It could well lead to reckless self-testing of impure trichosanthin powder and strengthen false hopes of many for a "magic bullet" cure.

Most importantly, an excess focus on GLQ223 could draw attention away from the therapies that are really killing people, from PCP CMV or MAI on the opportunistic infection front to homophobia, sexism and racism on the political front. We shouldn't repeat the mistakes of the past, when people put all their hopes into anecdotal or in vitro findings, magnified by rumor, about ephemeral wonder drugs such as AL-721, azuran or dextran sulfate.

Many conditions still demand treatment. Cure or no cure, the body politic is still diseased.

—M.H., 5/14/89
PROTOCOLS, which are the plans for clinical trials, always include a definite number of patients. This number is closely associated with the quality of the statistical data derived from the trial. Also included in protocols are the length of duration of the trial and the dosage and type of treatment. Trials can be as short as a few weeks to as long as three years. The duration of the trial is only a rough estimate of how long a trial will proceed. Trials can take much longer to complete, however, depending on the need.

Trials are open to enrollment to patients for an unspecified period of time. The time is dependent on how fast the target number of patients can be reached. The target number of patients could be as few as 10 patients or could be several thousand. When a trial reaches a target number it closes. However, sometimes the target number of patients is increased by the investigators because treatments are not successful in certain patients. In any event, the trial is completed when the last patient has finished his/her course of treatment, or when the trials is halted by regulatory body because the drug has been proven effective, or not effective or toxic. The data of a completed trial then is analyzed. If the drug has been show effective and comparatively safe, comprehensive documents are submitted to the Food and Drug administration (FDA). All this takes a considerable time. If patients enrolled quickly in trials and target numbers of patients are achieved early, trials will be completed faster. Completing trials faster will help speed research on other AIDS drugs. For the patients there will be access to FDA approved effective and safe drugs at an earlier date. The present system of enrolling patients in trials is not working for AIDS.

LOW NUMBER OF PATIENTS IN NEW YORK ACTG TRIALS

ON March 17, 1989, 6,000 copies of The New York Times were wrapped in an alternative publication called the New York Crimes. Reports indicated that some people made it halfway to work before they realized they weren't reading the real Times. We are unaccustomed to questioning what we read in the papers. Even though AIDS was about AIDS, it was presented in an acceptable and familiar way. The voice of authority was appropriated that morning, and the "news" was tucked under arms and into briefcases and read on subways. Because it looked like The New York Times, it became The New York Times, and commuters all over the city trusted what was written there. Unfortunately, the trust wasn't possible when a stranger handed out flyers on a street corner.

Little children all over America are raised with the idea that when they grow up, they will choose the government is doing what they want. They are told that if they focus their energies on their interests, they will develop expert knowledge, and that the knowledge will enable their children to work in an acceptable and familiar way. The voice of authority was appropriated that morning, and the "news" was tucked under arms and into briefcases and read on subways. Because it looked like The New York Times, it became The New York Times, and commuters all over the city trusted what was written there. Unfortunately, the trust wasn't possible when a stranger handed out flyers on a street corner.

People are influenced by what they see. The subliminal messages in the design of a deodorant can support the ideas of normalcy we are surrounded by. We are accepting of information when it is presented in places we expect to find it; subway ads, news papers.

Guerrilla information is the seizure of the voice of authority. It is speaking to the beast in its own language. Intervention into public dialogue is one of the methods of controlling the public debate in this country. It is a tactic used by the powers that be. We need to use it too. That is why we "advertise" our political ideas, why we choose public spaces to project them. The seductiveness of a well-turned phrase or good graphics can speak in some culturally
MARCH 28th at 7:00 am on a thousands of people converge...

protest the city's inadequate response to the AIDS crisis. The demonstration had been planned for several months at Act Up's weekly Monday night meetings. The protest, which was the largest AIDS protest in history with over 3500 attending and nearly 200 arrests for acts of civil disobedience, was called to bring attention to the Koch administration's murderous neglect of its citizens through budget cuts and inaction.

The protesters carried signs saying, "10,000 New York City AIDS Deaths, How'm I Doin'?" and used a front page headline of Mayor Koch saying, "I'm Heterosexual!" paired with such whimsical statements as "And I'm Carmen Miranda". Other visual props were used, such as cardboard boxes which said "NYC AIDS HOUSING", referring to the more than 8000 homeless people with AIDS that are living on the streets of New York. During the protest, large waves of demonstrators moved into the streets blocking traffic for hours in well organized acts of civil disobedience and were arrested. All were released several hours later after most were charged with disorderly conduct and resisting arrest.

The group charged the administration with not providing adequate community based medical centers, not providing safer sex education and transmission information to the groups which need it most (gay men and I.V. drug users) and pointed out that the Mayor cut $20 million from the city hospital budget last year which has translated into 950 capacity at most city hospitals, causing waits of several days for beds. The group demanded free treatment on demand for all drug users, more staff and beds in the hospitals, safe appropriate housing for all homeless people with AIDS and other related HIV illnesses, and preventive education which teaches protection and not morality.

Of those arrested approximately thirty were women. Following the women's arrest it was learned that most of the women were strip searched which is against N.Y.C. police procedure. The women arrested brought this to the attention of ActUp's attorneys and the media. The press picked up this story and exposed not only that strip searches for women are common but also that on intake booking sheets along with questions such as "Are you a gang member?" or "Do you have any tattoos?", was the question "Are you a homosexual?" This clear violation of peoples right to privacy is now being removed from intake booking forms thanks to the women of ActUp.

The demonstration marked Act Up's second anniversary. The first Act Up demonstration took place in March '87 on Wall Street on the day AZT was made available with 110 people attending. In March of '88 600 people showed up 3500 showed up this year which points out how much Act Up has grown in two years. There are now Act Up chapters in every major city and many minor cities in the U.S. and one in London.

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Seeing Red at City Hall

Seeing Red crossed police barricades onto City Hall grounds and, with DADA, marched eastward about 100 feet before being stopped, handcuffed, dragged by metal handcuffs and physically tossed into a paddy wagon. We were told by some of the arresting officers, "Fucking faggots, you deserve to die!" While we are pleased with our decision to take part in the initial wave, we feel we were unable to rely upon the preconceived coordination once we got to Broadway. Our action's location isolated us from the main picket, which, in turn, may have contributed both to our rough treatment and to some members' feelings of detachment. These feelings receded, however, when we returned with others to City Hall and disrupted the Mayor's afternoon press conference.
EYES ON MONTREAL
5TH INTERNATIONAL CONFERENCE ON AIDS

ACT UP TAKES OVER MONTREAL:

"Most journalists here would rather be covering China, or the Polish elections, or the ayatollah's death," said a reporter. "Anything but an AIDS conference without big medical stories."

ACT UP changed that. By week's end, AIDS activists had appeared on television and in print throughout Canada, in the U.S., and worldwide. And every reporter knew all about ACT UP.

The opening ceremony got the most coverage. We were the lead story on Canadian TV after the international news, and appeared on news in all major U.S. cities. Many of the stories had ACT UP interviews. Frequently-used pieces showed Tim McCaskell (from AIDS Action Now! of Toronto) opening the conference "on behalf of people with AIDS in Canada and around the world," as well as Coreps Thompson reading the Montreal Manifesto. Most TV coverage included the ovation we received from the delegates.

In print, it was the same. We finally made it into the Wall Street Journal (virtually every day). Even The New York Times mentioned ACT UP in Montreal. Local papers covered activists every day. Some highlights included:

- No less than two photos of ACT UP men kissing or hugging on the front page of the Gazette. However, the cropped photo included a sign saying "The world is sick..." without the bottom half ("...of AIDS hysteria" or whatever). You decide.
- Massive coverage of Stephen Joseph's testing announcement, most of it hostile towards the new policy.
- Local TV coverage of the Expos baseball game, where ACT UP gave away condoms and French-language safe-sex info.
- Serious coverage of the demonstration against exclusion of lesbian and prostitute-rights issues, which we feared would be ignored or trivialized.
- An article that quoted ACT UP members on the lack of safe-sex info in local bars.

- Several mentions of conference exclusion of PWAs. Tim Powers was spokesperson on that issue, and was interviewed when the conference agreed to free admission of 50 PWAs. A major coup!
- Stories on Mark Harrington's poster presentation ("Epidemiology and Punk: Viral Dialectics in the Soul Music of Prince") and on our "AIDS Buzzwords" poster.

ACT UP met with many of the 1300 reporters attending. We gave out 500 press kits, with Rolodex card and "AIDS Buzzwords" poster. We facilitated more than 100 interviews; many more occurred spontaneously. ACT UP photographers got photos into various papers, including the front page of the SF Sentinel.

Despite distributing nearly 3000 copies, we received little coverage of Treatment & Data's ground-breaking Treatment Research Agenda. However, delegates and reporters praised it wildly at a press conference we sponsored. We have mailed copies to major U.S. gay papers.

ACT UP Media Committee alerted the worldwide AIDS press to the British PWA who was strip-searched, handcuffed, jailed, and deported from Minneapolis on his way to a CD4 trial in San Francisco. A press conference was held, which led to a resolution by delegates condemning countries with travel restrictions based on HIV status. ACT UP's press release on the incident should appear in major U.S. gay papers.

Media Committee thanks ACT UP for approving the money for the Media Centre. The facilities were fantastic and helped us to stay on top of such a crucial week of events. It had five phones, three computers, and enough space for 100 people to meet each night. And thanks to Reaction-SIDA, the brand-new AIDS activist group in Montreal, for setting it up.

The ACT UP Montreal Media Savants: Jay Blotcher, John Voelcker, Eric Washington, Coreps Thompson, Jim Provenzano, John Davis, Tom Cunningham, Peter Bowen, and everyone else who helped out with media.
Just as there is a vacuum at the heart of the US AIDS establishment (as ACT UP ascertained in early May), so is there a vacuum amidst the international AIDS scientific community. Most scientists are still not used to dealing with people with HIV or with AIDS activists, and there was much grumbling about our prominence at the Montreal conference. Bigwigs like Gallo and Fauci groused that science must be conducted "in an atmosphere of calm," as though they have been immune from criticism from other scientists.

No one suspected that the opening night demonstration would be so successful. ACT UP occupied the stage before the conference opening, chanting and waving signs along with AIDS Action Now (Toronto) and Reaction SIDA (Montreal). Toronto activists declared the conference open and Conyers Thompson read the Montreal Manifesto of the International Rights of HIV-Infected People, first in French and then in English. This demo sparked tumultuous applause of delegates from around the world.

After we relinquished the stage we caused much consternation by occupying seats reserved for VIPs—the Canadian cabinet and conference chair Richard Morrisset (who just happens to be the CEO of Pfizer, Inc.). Activists from Chicago and New York addressed the delegates with a bullhorn. Later Kenneth Kaunda, President of Zambia, gave a moving speech about the need to convert first world production from arms to health care and evoked the memory of his fifth son, who died from AIDS.

Tuesday afternoon, ACT UP held a press conference announcing the release of its "National AIDS Treatment Research Agenda." The media center was packed. People who had been involved from the very start of the epidemic, including Dr. Joseph Sonnenbend, Vito Russo and Larry Kramer, spoke of the need for the AIDS community to be involved in AIDS research. The press conference was covered in Canadian newspapers.

ACT UP also gave the Agenda to US officials, including Assistant Secretary of Health James Mason, CDC AIDS activities director James Curran, NIAID director Anthony Fauci, FDA anti-viral drugs division head Ellen Cooper, and Congressional aides who work for Ted Weiss (D-New York), Henry Waxman (D-Los Angeles) and Nancy Pelosi (D-San Francisco). We set the stage for meetings in the very near future about these issues.

Jim Elgo presented 2 posters about "FDA Reform—an Activist Perspective on the Need for Legal & Regulatory Change." Iris Long presented 2 posters about the AIDS Treatment Registry, which distributed a draft copy of its first directory of AIDS drug trials in New York and New Jersey. Mark Harrington presented 3 posters about "Community Based Pneumo-Clinics as a Model for Cost-Effective Lowered Morbidity and Mortality in HIV Disease." Alternative Models for Clinical Trials: A Synthesis of Research & Health Care," and "Funk & Epidemiology: Viral Dialectics in the Soul Music of Prince." The last mentioned was written up in the Montreal Gazette.

New Treatment and Developments

THERE WERE HUNDREDS OF SPEECHES, POSTERS AND ABSTRACTS ABOUT NEW TREATMENT

DEVELOPMENTS. HIGHLIGHTS INCLUDED:

- GM-CSF is synergistic with AZT, enabling people to take 1/10 the dose of AZT alone for equal efficacy (but GM-CSF should not be taken without an antiviral, since some reports indicate it may encourage viral replication. Other reports contradict this.)
- Long-term AZT use causes muscle degeneration ("myopathy") in about 20% of those taking it for 8 months or more, including ARC patients.
- AZT analogues linked with a fat molecule ("phospholipid thymidine analogues") are absorbed into the membranes of HIV-infected cells such as the macrophage and the T4-cell, where they slowly release the drug into the cell over a period of days. This may mean smaller, less toxic doses of AZT can be taken.
- The Salk killed HIV core protein immunogen ("vaccine") is safe over long periods in HIV-infected people. Many subjects recovered a measure of immune function in a skin test to HIV-antibodies ("delayed cutaneous sensitivity") 4 Phase 2 trials will begin soon.
- DDC is effective and less toxic at a dose lower than used before. Wider Phase 2 trials will begin soon.
- CD4 injected subcutaneously (SC) has a longer half-life (4-8 hours) than IV, making it practical to take. No clinical benefits were seen in 2 of 3 studies.
- 2nd-generation CD4 products linking CD4 to an HIV-antibody (CD4 immunoaeshin) or to a toxic plant protein (CD4 exotoxin) are promising.
- Fluconazole is very effective against cryptococcal meningitis and against esophageal candidiasis (thrush).
- Itraconazole, a less expensive antifungal, is also effective against cryptococcal meningitis and thrush.
- Newer anti-MAI drugs like ansamycin, streptomyacin and clofazamine look effective.
- High-dose acyclovir (800 mg every 4 hours) prevented disseminated CMV infection, shingles and herpes simplex in 15 patients of New York researcher Craig Metzoka, MD.
- AIDS cases in minorities are significantly underreported even in areas with good reporting like San Francisco.
- The Tacoma needle exchange program has been successful, with no increase in HIV incidence or drug use.
- Both Fauci & Cooper said they support the idea of "parallel trials," in which a controlled trial would be supplemented by a trial open to those intolerant of standard therapy (e.g., AZT or Bactrim).
- No one mentioned Compound Q.
On Tuesday, May 30, Dr. Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases (NIAID) and head of the AIDS Program of the National Institutes of Health held a community meeting in New York City. Two-and-a-half hours of the 3-hour meeting were devoted to questions and (sometimes) answers. Because ACT UP members asked 3 of the first 4 questions, the ACT UP research agenda dominated the morning. One of the more startling moments of the morning occurred when Fauci quoted the ACT UP testimony before the Lasagna Committee (and acknowledged the quote) to support his contention that Treatment IND had failed. (Treatment IND is a program of the Food & Drug Administration of FDA that is supposed to make safe, potentially effective drugs available to people with serious or life-threatening conditions long before these drugs are fully approved for marketing.) He called for a new “parallel track” for AIDS drugs that are still investigational (still in clinical trials), a program that would actually do what Treatment IND had been intended to do. He said he did not think this track would deter people from enrolling in AIDS drug trials if the trials were well-designed.

In the ACT UP poster paper on FDA Reform that was presented at the International AIDS Conference in Montreal last week (and, in slightly different form, in the ACT UP treatment agenda released at the conference last Tuesday), ACT UP called for a program of parallel release for investigational drugs. Under the current system, phase 1 drug trials are primarily safety trials and only sometimes look for early signs of effectiveness. Therefore a drug, because it had proven safe and shown some efficacy, would be eligible for release outside the clinical trials system as early as the beginning of phase 2 trials. This is a remarkable development. T&D intends to see to it that the community of people with AIDS and AIDS activists have a voice in the formation of this new policy of a “parallel track” for investigational AIDS drugs, so that the fiasco of Treatment IND, a program that never lived up to anyone’s expectations, not happen again.

The single most exciting meeting that I attended in Montreal last week occurred after the conference had officially closed. Over lunch, 9 members of T&D who were still in Montreal agreed that the 5 drugs which we had (in our treatment agenda) called for immediate action on (GR: GM-CSF or G-CSF, Foscarnet, Fluconazole) were the drugs for which there was still the best evidence. We believe that by the time of the AIDS conference next summer in San Francisco, ACT UP should have secured the release of these drugs, or should have compiled a very full indictment of the party/ies responsible for thwarting their release. To that end, early this week, T&D is setting up meetings with the relevant parties (agencies and drug companies) to begin a concerted effort for their release and for a hand in the design of a “parallel track” for AIDS drugs.

This is not my last word on Montreal, and I’m sure my colleagues on T&D will have other things to say about it. In future T&D Updates, I hope to present short summaries of the new evidence released in Montreal concerning the effectiveness of the 12 drugs for which ACT UP has demanded special attention (the 5 for release mentioned above and 7 for expedited testing). These summaries will contain suggestions for ACT UP action. I also hope to give summaries on new evidence for old drugs (like acyclovir), and a few words on some of the more promising areas of drug development.

(Ami Ego) 539-2769)
PREAMBLE

HIV disease (infection with HIV with or without symptoms) is a worldwide epidemic affecting every country. People are infected, sick and struggling to stay alive. Their voices must be heard and their special needs met. This declaration sets forth the responsibilities of all peoples, governments, international bodies, multinational corporations, and health care providers to ensure the rights of all people living with HIV disease.

DEMANDS

1 All governments and all international and national health organizations must treat HIV disease positively and aggressively as a chronic, manageable condition. Ensuring access and availability of treatment must be part of the social and moral obligations of governments to their citizens.

2 Governments must recognize that HIV disease is not highly infectious. Casual contact presents no threat of infection, and irrational fears of transmission must be fought.

3 An international code of rights must acknowledge and preserve the humanity of people with HIV disease. This code must include:
   a) anti-discrimination legislation protecting the jobs, housing and access to services of people with HIV disease;
   b) active involvement of the affected communities of people with HIV disease in decision-making that may affect them;
   c) guaranteed access to approved and experimental drugs and treatments, and quality medical care;
   d) the right to anonymous and absolutely confidential HIV antibody testing. Pre- and post-test counselling must be available;
   e) the right to medically appropriate housing;
   f) no restriction on the international movement and/or immigration of people with HIV disease;
   g) full legal recognition of lesbian and gay relationships;
   h) no mandatory testing under any circumstances;
   i) no quarantine under any circumstances;
   j) protection of the reproductive rights of women with HIV disease, including their right to freely choose the birth and spacing of their children and have the information and means to do so;
   k) special attention to the unique problems and needs of intravenous drug users, including provision of substance-abuse treatment on demand;
   l) special attention to the unique problems and needs of prisoners with HIV disease and guarantees that they receive the same standard of care and treatment as the general population;
   m) the right to communication and all services concerning HIV disease in the language (written, signed or spoken) of his/her choice, through an interpreter if necessary;
   n) the provision of reasonable accommodation in services and facilities for disabled people;
   o) catastrophic immunity rights—the guaranteed right of people faced with a life-threatening illness to choose treatments they deem beneficial for themselves.

4 A multi-national, international data bank to make available all medical information related to HIV disease must be created. This includes all data concerning drugs and treatments, especially basic bio-medical research and the initiation of any progress of clinical trials.

5 Placebo trials must be recognized as inherently unethical when they are the only means of access to particular treatments.

6 Criteria for the approval of drugs and treatments should be standardized on an international basis so as to facilitate worldwide access to new drugs and treatments.

7 International education programs outlining comprehensive sex information supportive of all sexual orientations in culturally sensitive ways and describing safer sex and needle use practices and other means of preventing HIV transmission must be made available.

8 The unequal social position of women affecting their access to information about HIV transmission must be recognized and also their rights to programs redressing this inequality, including respect for women's right to control their own bodies.

9 Industrialized nations must establish an international development fund to assist poor and developing countries to meet their health care responsibilities including the provision of condoms, facilities for clean blood supply and adequate supplies of sterile needles.

10 It must be recognized that in most parts of the world, poverty is a critical co-factor in HIV disease. Therefore, conversion of military spending worldwide to medical health and basic social services is essential.
an unusually warm day, aged on New York City Hall to

"That's right we're bad, the biggest demo we ever had."
Ron Goldberg

"I was disappointed it was over so quickly. We need a new breakthrough in strategy. My ex-lover's ex-lover was there, but he might have just been cruising."
Mark Harrington

"We found ourselves (the Candelabras) in the street before we knew it and before other people were ready to support us and we ended up taking care of ourselves. We found ourselves far away from the group and it didn't matter whether it was 3,000 people or not we had to be trained ourselves to take care of ourselves in an ugly situation and we did it."
John Davis

"March 28 was fabulous and you know I don't use that word loosely."
Michael Musto

"People are changing their attitude about what they think going to a demonstration and getting involved in activism really means. 3,000 people shows it's not just a little handful of people willing to put their bodies on the line."
Michael Cowing

"I thought it was an absolute gas."
Michael Signore

"One of the things that we succeeded in doing is that we've actualized what we've been talking about which is reaching out to an incredibly broad constituency. We were reaching out to people who had never come to a demonstration before and they reflect areas outside the traditional AIDS groups, so to speak, we managed to integrated other issues."
Neil Broome

"I was really intimidated by the police presence. I've been to many demonstrations, but I don't think I have ever seen so many motorcycles, patty wagons, police in riot gear marching, full force, down the street."
John Andrisch

"WOMEN STRIPPED BEHIND BARS"
The hordes of media people at City Hall had their assignments lengthened a few days after word got out that 30 of the 40 women arrested at the March 28th action were illegally strip-searched at the two precincts we were taken to. The media hounds didn't seem to care much about the context of the arrests—the largest AIDS demonstration in New York City history; they were motivated by the inferred sordid production of 30 women taking off their clothes for prison guards.
But the ACT UP women would not cooperate with the sex-crazed tabloid mentality. "We were deluged with phone calls for interviews," said Catherine Saafield, "and everyone kept asking for the details of the search procedure. But we kept steering the framework by talking about AIDS issues, the demonstration, and the fact that the police do these searches with all women, regardless of what they're arrested for."

"CITY HALL FOLLOW-UP"
We are going to demand that every mayoral candidate state publicly what they are going to do in reference to our list of demands and what they are going to do in reference to the healthcare system.
We are addressing every single mayoral candidate this week with a letter telling them 3,000 people were at City Hall. Explaining why we were there, giving them a copy of our list of demands, our City Issues Handbook, a copy of our Women and AIDS Handbook, and demanding that they respond within 10 days. We want a meeting with them and several members from ACTUP. We will demand that they make a public response as to what they are going to do about the AIDS crisis in this city. If they don't make a public response or they don't adhere to our list of demands, we will start hitting every single one of their public appearances, having sit-ins in their offices, phone zaps, etc.
We want to make sure that every mayoral candidate and every candidate for any position in city government is accountable for dealing with the AIDS crisis. They won't stop us, we will do zap after zap if the AIDS crisis is not handled. It's not enough to tell us that the blame is on the state government and the federal government, that is not an excuse. It is their responsibility to get that money out of the federal government.

"WOMEN'S RIGHTS"
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Over 200 people attended the two marathon Women and AIDS Teach-Ins held in early March. A clear message from the Teach-In was that long-standing and institutional manifestations of sexism and women's oppression must be taken into account when talking about women and AIDS. Centuries of a patriarchal medical establishment have long taken from women control over our own bodies. Issues of race, class, sexism, heterosexism, poverty, housing and child care are magnified by the AIDS crisis; all along, women become disposable.

Women die three times more quickly than men after being diagnosed with AIDS and many more women die of HIV-related illnesses without ever being diagnosed at all. Women are routinely excluded from drug trials—i.e., treatment—if deemed to have "child bearing potential." Yet again, the concept of an unborn fetus is more important than the life of the woman, her ability to make decisions about her own health is never considered. ADAPT estimates between 25,000-40,000 HIV+ women drug users, yet the City provides no funding at all for programs which specifically address women with AIDS.

Safer sex campaigns tell women it's our responsibility to make sure our male partners use condoms, but explain nothing about negotiating safer sex. We can only push men to assume responsibility. Lesbians don't even exist in the eyes of the CDC, which has no categories for women who have sex with women and refuses to study the possibility of human-to-woman transmission, despite having at least 4 known cases where it has occurred. Currently, one in eight PWAs are women, but among teenagers the ratio is one in three. Of the 3 million women with AIDS in New York City, most are poor; none are being served. But we are not disposable; we are fighting for our lives too.

Produced out of the Teach-In is the monumental Women and AIDS Handbook, an activist-oriented document which includes information you won't find elsewhere. Easily surpassing its second printing, this is our major work on the issue. Currently available for $8 more if ill in its Xerox form; look for publication in the fall.

We distributed flyers at the GMHC AIDS Walk on May 22nd to highlight the lack of funding for women-oriented AIDS organizations, such as the Women and AIDS Resource Network (WARN).

The "Content to Bename the Dental Dam" is in its closing moments. Entries have included "Box Tops," "Chit Capes," and "SisSheik." The contest was initiated to drum up money for a mini metrix latex accoutrement used for oral sex with a woman partner. Look for a loud and proud event to announce the winners.

The Caucus is producing a Lesbians and Safer Sex Flyer for Gay Pride Day and will sponsor a women's committee of the Women's Unity Roundtable on Thursday, July 13 at the Gay and Lesbian Community Center. Last year's forum featured Denise Riddle from the Community Health Project, but this year we're prepared to do it ourselves.

There is a new "sub-sub-affinity group" from DIVA TV (Damed Interfering Video Activists) called LAPIT TV (Lesbian Activists Producing Interesting TV). You don't need to be a member of ACT UP to get involved, but if you are you can be dubbed LAPITTUP. The group is producing a video featuring the Women and AIDS Teach-In and the Strip Search saga.

Finally, the Women's Caucus now has a regular meeting time! We welcome all women to these pot-luck meetings. We will be held on the first Friday of every month. Call the ACT UP number for details.

There are thousands of people, even in New York, who have never heard of Act Up. Thousands more have never seen or heard about one of our demonstrations. Thousands still that never have been hit by the facts of undercovered drug trials or the bureaucratic red tape stalling the drug approval process. Millions more don't know or don't care that poor people, women, people of color and children have inferior or no medical care because they can not afford insurance. These are our problems. Big problems.

The Caucus Committee exists to solve these problems of public ignorance. We are the committee which is charged with getting information out of Act Up and into peoples hands. We have succeeded in getting this newsletter into yours. What you hold in your hands is a tool of outreach. However, our mission does not stop there. In the past six months we have had members of ActUp, through our Speakers Bureau subcommittee speak at over 40 universities and organizations. Many of these speaking engagements resulted in ActUp chapters being formed. A recent speaking engagement resulted in a group of students at Pace University at their school, for having told AIDS "jokes" in class the previous week. Several recent and upcoming speaking engagements on Long Island, which has a larger drug load than many major cities, is resulting in a network of individuals and organizations which will undoubtedly result in the formation of another Act Up chapter.

Outreach's strengths lie not only in its newsletter and Speakers Bureau, but also in our ability to mobilize/publicize/educate people about an upcoming ActUp demo. We do this by leafletting. We do this by wheatpasting. We do this by any innovative way we can. Tabling, bar raids, guerilla subway and bus advertising are part of our repertoire. All this takes Act Up members getting off the streets. We are always looking for new people and new ideas. Outreach is only as powerful as you and I make it. Some of our upcoming activities deal with, fostering new ActUp chapters, setting up video library and maintaining better contact with and offering support to other AIDS activist groups. Sound like tons of work? It is for the dedicated few. Are you interested? Call us now. It is for the dedicated few. Are you interested? Call us now.

The above action illustrates how we channel anger into direct action. The chants and energy expressed at City Hall that day may have dissipated but the facts remain:

Anonymous Testing and counseling has been policy in NYC since the beginning of the AIDS epidemic. A system in which only an identification number is used, anonymous testing allows those people who wish to be tested to do so without fear of disclosure and discrimination.

Confidential Testing requires the use of your name and Joseph's plan would require your name to be reported to the Department of Health if you test positive for HIV antibodies. The risks of abuse of this information, and the reports in other states of people being fired, visited at work, and harassed after their test results were disclosed are too great.

Joseph says that if names are kept, that better follow-up and treatments could be administered. Of nine years into the AIDS crisis NYC cannot provide the most basic services, how do they think they will provide the "luxury" of adequate treatment.

Those who are most at risk will be driven underground, afraid of being stigmatized, thrown out of their homes and jobs, with no available treatment options.

CALL COMMISSIONER JOSEPH:
TELL THE COMMISSIONER THAT ANONYMOUS TESTING MUST BE EXPANDED NOT ELIMINATED.
COMMISSIONER JOSEPH'S OFFICE (212) 566-7150
HEALTH DEPARTMENT COMPLAINT LINE (212) 285-9503

outrage, anger and power in front of City Hall. We would send the message loud and clear: "We're Act Up, we're pissed, we want AIDS treatments not a list."

But we had to mobilize quickly. Within 72 hours we had to publicize, organize and educate people on anonymous testing and the issues at stake. With the plan of action set, Act Up went to work. The following Friday 25 members arrived at the drug logistics, hammer out a fact sheet, and plan visuals, chants and a media blitz. At the same time the Outreach committee went to work producing and getting into hands of car and people's hands an invitation to demonstrate.

All this was accomplished, on the most part, not by the seasoned Act Up veterans, most of whom were still in Montreal, but by the standing room only showed that the news from Montreal had generated. Many of them had never been involved in planning a Zap before let alone doing actual logistics needed to pull off a demo.

Standing Thursday morning over 200 enraged activists swarmed New York's City Hall. The New York media, tipped off by the excellent work of Act Up's media committee, were at City Hall in full force. Also attending were New York's finest. Little were they prepared for the deep emotional and political convictions of those present, testing must remain anonymous and confidential. The boys and girls in blue were shocked and dumbfounded to find that we did not intend to remain between their prescribed boundaries. Time and time again we eluded their corralling efforts. Finally we took our cause to the streets and marched to the Department of Health. We converged on Centre Street stopping traffic, irritating the police and invigorating our slogans. Powerful and strong we marched chanting to the steps of the Health Department. "First you don't exist, now you're on the list." "Act Up, Fight Back, Fight AIDS." The scenario was repeated at 4:00 with the addition of a long march to the site of the Stonewall riots at Sheridan Square.

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UNITY FOR LIFE BLOSSOMS

"The need for putting aside our personal differences and uniting our efforts to achieve a comprehensive strategy for access to improved quality healthcare for everyone."

Sidique A. Wai
President of Peoples Alliance Community Organization, Inc. Spokesperson for City Wide Coalition Against Health Care Genocide

Why do we have to be united today? In the 1970s community based organizations had to resist the sedation of minorities with Methadone. In the 1980s, the only legalized treatment for poverty level PWA Latinas and African-Americans is the frequently toxic drug AZT.

- We need Medicaid coverage expanded to include alternative treatments such as acupuncture and Chinese medicine.
- Clifford Goodman, Executive Board
- Member Act-Up Majority Actions Committee
- We also have a right to fight in the battle to overcome the AIDS Crisis through providing informative outreach and by stressing the importance of selfhelp and empowerment. This is the only way to get people to help themselves. So Act-Up, you are always welcome here!
- Yvonne Durand, Director of Education at BATF (CSP)
- To get to the root of the problem, communities must work from within, because who better qualifies to address a problem than those who have dealt with and sometimes had to overcome it themselves.
- Marjoline Alexis, Assistant Director of Education, BATF (CSP)

- Risk factors must include lack of access to health care for the poor people all over New York—connecting with existing health care struggles taking place in communities of color is one important area for AIDS activism.
- Ray Navarro Act-Up Majority Actions Committee
- We support our children and not judge them. We can't wait for the hospitals to improve. We must also take a stance and help our own.
- Mildred Pearson, leader of mothers' support group, BATF (CSP) assistant and mother of a deceased PWA.

Helping our own is what ACT-UP/BATF (CSP) is all about, organized and sensitive to the rights of community members and not allowing differences to divide. One recent action was directed at Kings County, a City hospital in Crown Heights which had poor treatment for AIDS patients. PACO-Inc. brought a coffin to the hospital's doorsteps and as a result major changes have been made.

- If you want to hide things from our people who the disease is hitting the most, put it in the newspapers. We must focus on our churches, the radio and communication from community to community. The thing that allows politicians to get away with murder is because they go to communities separately negotiating and throwing a few crumbs here and there. So our health care plans must be inclusive of all communities so they have no place to hide!
- Sidique A. Wai

- Building relationships outside our own communities is one of the most important aspects of the AIDS struggle. ACT-Up has tons of information about AIDS. But unless we can reach out into the other communities and get this information to people who need it, the information becomes useless.
- Sharon Traumula

What is proper outreach?
- ...dropping our intellectual facades and spelling it out clearly. When speaking in a community, find a common ground to get the wheels moving and make what you say something that hits home.
- Jon Baxton, Community AIDS Worker at BATF (CSP)
- We are no longer a minority in this struggle to end the AIDS crisis. We are a majority, 60% of the AIDS community and there is strength in our unity.
- Karim Sharji, Brooklyn Outreach at BATF (CSP)

- We can learn so much from the Gay Community. When this disease first hit us, it was thought to be 'their' problem. They hated and made some strong strides because they realized that the lack of concern in other communities and city/state government was a silent voice saying, 'Let them all die.' The same is happening to our minority communities, both heterosexual and Gay, and unless we overcome the fear of AIDS within our own communities, the AIDS crisis will wipe us out. We can't take the attitude that AIDS only affects people with different lifestyles because we would only be fooling ourselves.
- Diana Roberts, member of PACO-Inc., and one of the coffin bearers at Kings County Hospital action

- Built up and well developed approach emerging where we can become more powerful and get things done.
- David Bay, WBAI

Our vision was a good summing up, and Majority Action Committee members look forward to nourishing the plants of unity that have finally broken the brown soil of our mother earth.

Blaine C. Mosley
Majority Action Committee
from a Community Speak out
March 18, 1989

SUPPORT US

☐ I have enclosed a check for
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ACT UP, 496A Hudson St., #G4, N.Y., N.Y., 10014.