AIDS REPORTING IS OUT OF ORDER
On June 30th, 1986 (eighteen months ago and 7 years into the epidemic) the National Institute of Allergy and Infectious Diseases (NIAID) started what was suppose-to-be a comprehensive national program to test promising new treatments for AIDS in clinical trials (1). Fourteen medical centers across the country were designated AIDS Treatment Evaluation Units (ATEU). Five year contracts were awarded totaling 100 million dollars. The program was later expanded to 19 ATEU’s (January 1987) with an additional $37.5 million. ATEU’s were established at Albert Einstein, Mount Sinai, New York University and Memorial Sloan-Kettering in New York City. The Medical Center at Rochester University is the fifth ATEU in New York State.

While the ATEU members were designing protocols (1) in the summer of 1986, the Burroughs Wellcome AZT (Zidovudine) clinical trial was terminated prematurely on September 19, 1986 because the drug was shown to prolong the life of some Persons With AIDS (PWAs). Because of these results, The Director of NIAID’s AIDS Treatment Program, Dr. Anthony Fauci, decided with his advisors that the ATEUs should test almost exclusively AZT in the first year, and determine its effectiveness in other patient populations. The first clinical trial at NIAID began in January 1987.

Dr. Fauci announced in December 1987, that the the 19 ATEUs will be combined with the newly created 17 Clinical Study Groups (CSG) also involving certain hospitals. These 36 clinical testing units will be called AIDS Clinical Trial Groups (ACTG). Another $100 million will be added to this combined ATEU/CSG program. The new groups in New York City will be at St. Luke’s/Roosevelt Hospital, and Cornell University Medical Center.

These are the facts:

- OVER 52,000 people have AIDS and 27,000 have died of AIDS: men, women and children. 300 PEOPLE DIE EACH WEEK, ALMOST ONE EVERY HALF HOUR. New York State leads the nation in the total number of cases of AIDS (13,483, 25%). Over 4,100 cases of AIDS in women have been reported. As high as 2 million women, men and children may be infected with HIV virus.

- There are NO investigational AIDS drugs available on a compassionate basis for dying People With AIDS (PWAs)? The drugAZT is too toxic for 50% of the AIDS patients. Nationwide, AIDS patients have access to only ONE ATEU TRIAL having 25 patients slots for ONE NON-AZT DRUG (DDC or dideoxycytidine). PWAs lack of access to other potentially helpful drugs is INHUMANE.
The FDA says that keeping drug companies informed of their policies. Why did they not inform the manufacturer of Imuthiol (3) of the conference of the Treatment IND conference ("Making Investigational New Drugs Available to the Desperately Ill")? The conference is being held on February 16 & 17th, 1988 in Washington D.C. and cosponsored by the FDA along with the AMA.

Women, children, babies, black and latino people, and drug users are underrepresented in the ATEU trials. There is no tracking system to prevent discrimination. Government agencies such as the FDA have guideline which support discrimination. Many trials nationwide including government trials EXCLUDE WOMEN AND OTHER PEOPLE people: ampligen (DUPONT), thymopentine (ORTHO), isoprinosine (NEWPORT), Imuthiol (MERIEUX), CL246,738 (LEDERLE),alpha interferon (NIAID), etc.

People with AIDS (PWAs) are being asked to participate in cruel, placebo controlled ATEU trials (2). For example, in protocol 005, a clinical trial using the drug AZT for patients with HIV Central Nervous System infection, 1/3 of these are given placebo for 4 months. The New York State ATEU's have enrolled only four patients in this trial in four months.

Too few new drugs are being tested. As of February 5, 1988 nationwide, there were 2,962 patients in 25 ATEU trials. FOUR trials testing only AZT have 83% of the total of 2,445 patients. EIGHT trials have less than TEN patients enrolled. Nationwide 94% of the patients are trials testing AZT or AZT in combination with another drug.

As of February 5, 1988, New York State has 748 patients enrolled in these trials 98% of which are AZT trials. Why aren’t the OVER FORTY other promising AIDS drugs with FDA approval tested in people at the ATEUs?

Too few patients are enrolled. Important ATEU protocols which have been open for months have few patients enrolled. Open over 6 months the protocol 004, which uses a combination of two drugs, DHPG which could stop the progress of blindness due to CMV, and AZT which could stop the progress of HIV infection has only 23 patients out of 60. Only 16 patients are registered in this trial in New York State. Other protocols enrolling LESS THAN FOUR PATIENTS A MONTH for the past five months are: 003, 005, 008, 009, 014 and 017.

After 1 year of active protocols, NO RESULTS from an ATEU trial have been officially published. An important trial involving AZT (019) may take over 3 years to complete because of the lack of patients according to an article the New York Times (12/29/87).

After 8 years and the development of over 30,000 cases of the deadly pneumonia PCP, why does the ATEU’s have NO trials testing prophylactic drugs (4), such as pentamidine?
Why isn’t there a coordinated AIDS Treatment Program, including
drug companies to design the best clinical trials for a truly
National effort? Many drug company trials exclude women and use
placebos. Drug companies blame the Food and Drug Administration
(FDA) for this.

There is NO UP-TO-DATE, ACCURATE, RELIABLE REGISTRY of AIDS
CLINICAL TRIALS available to doctors, patients, NIAID AIDS
coordinators and others. The government’s databases PDQ and
CLINPROT are NOT ADEQUATE. One result of this lack of information
is that patients can’t find trials and doctors can’t find patients.

The Food and Drug Administration (FDA), as a repository of all
clinical trial information, has NO SYSTEM in place to make
important, trial information available and will not.

The FDA’s rules are not clear to drug companies and doctors, and
NIAID scientist alike, and are unworkable in this crisis. Why must
drug company trials of the three promising ampligen, ribavirin and
DHPG be repeated because of faulty protocol design? DESPERATELY
NEEDED is more cooperation between the FDA, NIAID other government
agencies and drug companies.

Definitions:
1) A clinical trial is a drug test on people over a specific length
of time done in hospitals, and other institutions. The protocol
outlines the procedures of this test.
2) A placebo is a "false drug". Patients who receive placebo do not
receive the treatment that has been proven somewhat efficacious.
3) Personal communication with Merieux Institute spokesperson
4) A prophylactic drug is one which prevents the person from
developing the infection.

EXHIBITS:
1) EXHIBIT A- AIDS TREATMENT BRANCH - LIST OF ACTIVE AND CLOSED
PROTOCOLS dated 2/5/88
2) EXHIBIT B- SUMMARY OF PATIENTS ACCRUAL BY ATEU AND PROTOCOL
DATED 2/5//88
3) EXHIBIT C- ACTIVE AND PENDING PROTOCOLS 2/5/88

JOIN ACT UP IN THE STRUGGLE TO OVERHAUL THIS NATIONS AIDS
TREATMENT PROGRAM

ACT UP
496A HUDSON STREET, SUITE G4
NEW YORK, NY 10014
212 533-8888
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### SUMMARY OF PATIENT ACCRUAL BY ATEU AND PROTOCOL 2/05/88

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X = will not participate
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**SUBTOTAL** (page 3) 526 00 13 03 00 01 12 2962

- *x* - will not participate
- *P* - pending; paperwork incomplete (approved consent form and/or IRB approval)

**NOTE:** 14 new patients have been added through the CSG's. They will be added next week.
<table>
<thead>
<tr>
<th>PROTOCOL (cmte)</th>
<th>PROTOCOL TITLE</th>
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<tr>
<td>ATEU 001 (AV)</td>
<td>Placebo-controlled trial to evaluate AZT in patients with AIDS-associated KS</td>
<td>Closed, no longer accruing</td>
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<tr>
<td>ATEU 002 (AV)</td>
<td>Randomized two dose comparison study of AZT in patients with AIDS post PCP</td>
<td>Closed, no longer accruing</td>
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<tr>
<td>ATEU 003 (PEDS/PH)</td>
<td>Phase I evaluation of AZT in children with AIDS or ARC</td>
<td>Active, accruing patients</td>
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<td>ATEU 004 (PH)</td>
<td>Phase I studies of the combination of AZT and DHPG in patients with AIDS and CMV</td>
<td>Active, accruing patients</td>
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<td>ATEU 005 (NEUR)</td>
<td>Placebo-controlled, double-blind trial of AZT in AIDS dementia and HIV infection of the CNS</td>
<td>Active, accruing patients</td>
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<tr>
<td>ATEU 006 (ONC)</td>
<td>Phase II study of weekly doxorubicin treatment of AIDS-associated KS</td>
<td>Active, accruing patients</td>
</tr>
<tr>
<td>ATEU 007 (PH)</td>
<td>An open phase-1 trial of combination therapy with AZT and desclovir in patients with AIDS or ARC</td>
<td>FDA has on hold, pending safety data</td>
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<tr>
<td>ATEU 008 (ONC)</td>
<td>Chemotherapy, radiotherapy and AZT for high-grade lymphoma in AIDS-risk group members</td>
<td>Active, accruing patients</td>
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<tr>
<td>ATEU 009 (ONC)</td>
<td>Chemotherapy and AZT for AIDS-related primary CNS lymphoma</td>
<td>Active, accruing patients</td>
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</table>
ATEU 010A (PH) An uncontrolled trial to evaluate the pharmacokinetics and the pharmacodynamics of AZT and ACV given concomitantly to patients with HIV infection

ATEU 011 (PH) Dideoxycytidine pharmacokinetics in HIV-infected patients

ATEU 012 (AV) A multicenter dose-ranging clinical trial of ddC in advanced ARC

ATEU 013 A phase I study of AZT and human interferon (recombinant alpha-2A and Lymphoblastoid) in the treatment of AIDS associated KS

ATEU 014 (ONC) A phase I study of AZT and human interferon (recombinant alpha-2A and Lymphoblastoid) in the treatment of AIDS associated KS

ATEU 015 (OI) Foscarnet treatment of serious CMV retinitis infections in patients with AIDS

ATEU 016 (AV) AZT treatment of early ARC

ATEU 017 (PH) Phase I trial to evaluate AZT in patients with hemophilia

ATEU 018 (OI) Escalating doses of IV trimetrexate for previously untreated PCP in AIDS, with subsequent comparison of IV and oral pharmacokinetics

ATEU 019 (AV) Safety and efficacy of AZT for asymptomatic HIV-infected persons
### AIDS TREATMENT BRANCH -- ACTIVE AND CLOSED PROTOCOLS

**2/05/88**

<table>
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<tr>
<th>PROTOCOL NUMBER</th>
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<th>PARTICIPATING INSTITUTIONS</th>
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<td>ATEU 001</td>
<td>Placebo-controlled trial of AZT for KS</td>
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<tr>
<td>ATEU 002</td>
<td>Two-dose trial of AZT in AIDS post-PCP</td>
<td>Closed</td>
<td>575/482</td>
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<tr>
<td>ATEU 003</td>
<td>Phase I evaluation of AZT in children with AIDS or ARC</td>
<td>Miami, Duke</td>
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<td>ATEU 004</td>
<td>Phase I studies of the combination of AZT and DHPG in patients with AIDS and CMV</td>
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<td>ATEU 005</td>
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<td>ATEU 009</td>
<td>Chemotherapy and AZT for AIDS-related primary CNS lymphoma</td>
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<td>ATEU 010 A</td>
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<td>ATEU 011</td>
<td>ddC pharmacokinetics in HIV-infected persons</td>
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<td>ATEU 012</td>
<td>A multi-center dose ranging clinical trial of ddC in advanced ARC</td>
<td>Stanford, Miami, UCSD,</td>
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<td>ATEU 013</td>
<td>Phase 1 study of AZT and human interferon (recombinant alpha-2A and lymphoblastoid) for KS</td>
<td>Miami</td>
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<td>ATEU 014</td>
<td>A phase I study of AZT and human interferon (recombinant alpha-2A and lymphoblastoid) in the treatment of AIDS associated KS</td>
<td>MSKCC</td>
<td>25/66</td>
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<td>ATEU 015</td>
<td>Foscarnet treatment of serious CMV retinitis infections in patients with AIDS</td>
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<td>ATEU 016</td>
<td>AZT treatment of early ARC</td>
<td>All ATEU sites</td>
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<td>Phase I trial to evaluate AZT in patients with hemophilia</td>
<td>Rochester</td>
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<td>ATEU 018</td>
<td>Escalating doses of IV trimetrexate for previously untreated PCP in AIDS, with subsequent comparison of IV and oral pharmacokinetics</td>
<td>USC, NIH</td>
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<td>ATEU 019</td>
<td>Safety and efficacy of AZT for asymptomatic HIV-infected persons</td>
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<td>ATEU 022</td>
<td>Dose-ranging trial of AL-721 in PGL and ARC</td>
<td>Mt. Sinai, MSKCC, Minn</td>
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<td>ATEU 025</td>
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<td>Harvard, UCSF, Washington</td>
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<td>ATEU 026</td>
<td>Maintenance therapy for cryptococcal meningitis after initial IV induction with amphotericin B vs fluconazole</td>
<td>UCSF, MSKCC, UCLA, USC, Boston, Texas, Miami, NYU, Mt. Sinai, Rochester</td>
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ATEU 027  Phase I trial of AZT and probenecid/quinine

ATEU 028  Foscarnet dose-response in symptomatic patients

JHU 12/12

Minn, Tulane, USC, UCSD, MSKCC, Mt. Sinai, Washington 0/80

TOTAL NUMBER OF PATIENTS ENROLLED 2,962

NOTE: 14 new patients have been added to the CSG's. They will appear on the chart next week.
On March 20, 1987, the Food and Drug Administration approved the drug, AZT, for treatment against AIDS. AZT is a highly toxic chemical tolerated by only 50% of AIDS patients. In the entire year since then, no other drugs have been approved to fight the HIV virus, even as the FDA has touted its "streamlined" drug approval process. Meanwhile, DHGP, (Ganciclovir), was rejected for approval in spite of two years of research under a compassionate use protocol of over 2400 persons with AIDS who showed significant improvements in the study. DHGP is used to prevent imminent death and blindness in persons with AIDS with CMV infection. This disapproval of DHGP is especially shocking since no other drug has proven effective in treating CMV, a deadly and highly prevalent infection in people with AIDS.

NIH: SHORT SIGHTED RESEARCH

The National Institutes of Health (NIH) are responsible for the government's clinical trial testing programs of experimental drugs to fight AIDS. To date, the NIH has provided only expanded clinical trials of AZT, thereby blocking the trials which could determine the usefulness of over 40 other drugs believed to be effective by thousands of persons with AIDS and their physicians across the country. 87% of the over 3000 patients in the NIH's AIDS Clinical Trial Groups (ACTG), are currently enrolled in studies of AZT. The remaining 13% are enrolled in extremely limited preliminary trials of drugs not thought to be curative.
The NIH's wholly committed efforts must be in basic research: the development of drugs to specifically stop the HIV virus. Currently under consideration are drugs which had previously been found to be too toxic in treating cancers and other illnesses. Unscrupulous drug companies have exploited this as an opportunity to recoup their losses, promoting these stockpiles of worthless drugs as anti-HIV agents. The NIH has failed to effectively differentiate between useless and promising drugs.

REAGAN'S HOLLOW AIDS BUDGET

The Reagan Administration proudly announced a $2 billion budget for AIDS in fiscal year 1989. However, looking closely at a detailed breakdown, only $700 million will be spent on drug development and basic research; much of which will not be spent in fiscal year '89. This budget does not increase the number of employees working on AIDS drug development programs, in sharp contrast to the President's own Commission on AIDS which has called for a dramatic increase of full-time personnel in the FDA and NIH.

THE LEGISLATIVE AGENDA: THREATENING CIVIL RIGHTS

Legislatures across the nation are considering and passing laws in unprecedented numbers to restrict the rights of Americans. Promoted under the banner of "public health policy", these threatening measures do little to protect the public and are counter to the recommendations of the nation's top public health experts.
Legislation calling for mandatory and/or routine testing, contact tracing, quarantine and other draconian measures abuses civil rights, and spends vast sums—monies which should go to the care and treatment of persons with AIDS.

THE LEADERSHIP VACUUM

There is an emergency need for a federally-appointed person or agency responsible for coordinating the nation's response to the AIDS epidemic. In the absence of such an appointee, many areas of urgent and life-saving work slip through the cracks of government bureaucracy.

THE FAILURE TO COMMUNICATE

The NIH does not monitor closely, or even know, what private pharmaceutical companies are developing in the fight against AIDS. There is no all-inclusive registry of government and private drug companies' research available to medical experts, physicians and their patients. Nor is there adequate involvement in or tracking of research developments unfolding around the world. The NIH is not addressing this tragic lapse in vital national and international communication.
MASSIVE AIDS PROTEST

ON WALL STREET

What: Massive AIDS demonstration and civil disobedience on Wall Street

When: 7 to 9 A.M., Thursday, March 24

Where: Begins at Trinity Church, Wall Street and Broadway

SEVERAL HUNDRED PROTESTORS WILL CONVERGE ON WALL STREET TO DEMAND MORE ACTION AND AN END TO INEFFICIENCY BY BOTH GOVERNMENT AND THE PRIVATE SECTOR IN DEALING WITH THE AIDS EPIDEMIC. MANY PROTESTORS, INCLUDING PEOPLE WITH AIDS, HAVE PLEDGED TO COMMIT ACTS OF CIVIL DISOBEDIENCE. THIS PROTEST BY ACT UP MARKS ONE YEAR ANNIVERSARY OF FIRST AIDS DEMONSTRATION, ALSO HELD ON WALL STREET. PROTESTORS WILL RENEW AND ADD TO DEMANDS OF A YEAR AGO, INCLUDING:

--- Increased government spending for AIDS programs

--- Release of funds already appropriated

--- Faster approval of AIDS drugs and treatments (of the more than 40 drugs that have shown promise, only a few are being tested)

--- An end to drug company exploitation of the AIDS crisis (AZT, manufactured by Burroughs-Wellcome, costs more than $8,000 a year)

--- A truly coordinated effort by government and the private sector to find a cure for AIDS.

ACT UP IS A NON-PARTISAN GROUP COMMITTED TO DIRECT ACTION TO END THE AIDS CRISIS.

For more information: Ron Goldberg, (212) 246-2879
Alan Klein, (718) 956-4916
Acting Up to Fight AIDS

A group's angry tactics

On a Sunday afternoon, about 50 Bostonians, mostly gay men, gathered outside the Brookline home of Gov. Michael Dukakis. Wearing lab coats and stethoscopes, they set up intravenous-feeding equipment on the sidewalk and chanted, "Leading the nation is really hard when you can't fight AIDS in your own backyard."

Gay activists declared it Condom Day at New York's Shea Stadium, and the rented electronic billboard flashed messages about safe sex. As the protesters shouted slogans during a Mets-Astro game, baseball fan Kevin Mirabile complained, "AIDS is a fearful topic. This is totally inappropriate."

For the members of a gay organization called ACT UP, all is fair in the war against AIDS. In the year since it was founded, ACT UP (AIDS Coalition to Unleash Power) has deliberately trespassed the bounds of good taste in a campaign to broaden the government's role in fighting the deadly epidemic. Members have necked in the office of conservative Sen. Jesse Helms and thrown condoms at Cosmopolitan magazine editor Helen Gurley Brown, who published an article minimizing the threat of AIDS to heterosexuals. Recently some 60 demonstrators showed up at a U.S. Commission on Civil Rights hearing on AIDS wearing clown masks and shouting "Shame! Shame! Shame!" Using protest methods that are part guerrilla warfare, part civil disobedience, the group has provided an outlet for its members' anger and fear about dying at an early age.

Testing positive: It has also reawakened an activist spirit in the homosexual community. While militants rallied for sexual freedom in the late '60s and '70s, gays today feel they are struggling for their very survival. The New York chapter of ACT UP, founded by gay playwright Larry Kramer, has about 1,000 members. Of its members, a third have AIDS, and two-thirds have tested positive. Viruses. Most are young professionals who "have never done anything political beyond casting a vote," says Mark Kasparopoulos of the Los Angeles chapter. "But then people started dying and they've found they have to respond."

ACT UP's basic modus operandi is the "zap": a media-grabbing protest aimed at public figures or institutions that the group feels should be doing more to combat AIDS. Activists have staged "die-ins" at the Dallas City Hall and the Food and Drug Administration's Los Angeles headquarters, leaving the outlines of hundreds of bodies scrawled in red chalk on the sidewalk. Dissatisfied with AIDS funding in New York City, ACT UP plans to heckle Mayor Ed Koch at next week's opening ceremonies in honor of the city's Gay and Lesbian Pride and History Month. Some gay leaders have called the upcoming "zap" divisive.

Whether ACT UP can make a difference remains to be seen. The mainstream Gay Men's Health Crisis (GMHC) says that ACT UP's tactics complement their own fund-raising efforts and legislative testimony. "Their actions show the humanity behind the statistics," says GMHC spokesman Robert Peterson. ACT UP has also assembled a cadre of self-taught medical experts who have lobbied to get experimental AIDS drugs into the marketplace more quickly. But its controversial methods sometimes backfire. Though ACT UP "has made a significant contribution to our fact-finding process," says Thomas Brandt, spokesman for the presidential commission on AIDS, the group has "personally offended" some members. Susan Prado, acting staff director of the targeted Civil Rights Commission, says the group "doesn't help its own cause by focusing on the disease's homosexual aspect."

For now, ACT UP plans to keep the heat on. In California, 41 demonstrators were arrested outside the governor's office last month. As frustration over AIDS continues to grow, the group may take a more violent turn. "Who's to say that in a year our demos won't be more confrontational," says Dallas activist William Wayvorn. "Do not underestimate the level of anger that exists here."

Eloise Salholz with Peter McKillop in New York and bureau reports

New York's $5.3 Billion Nuclear Waste

The nuclear power industry received another blow last week when New York state agreed to buy a piece of Long Island real estate valued at $5.3 billion. The property, the five-year-old nuclear power plant at Shoreham, a small town on Long Island. The selling price: $1. The lopsided deal, part of a proposed settlement between the state and the financially troubled Long Island Lighting Co. (Lilco), headed off a grassroots movement for a public takeover of the investor-owned utility. In exchange, Lilco received guarantees that it can remain independent and increase its rates—already the nation's second highest—over the next three years, in part to cover the costs of the plant.

Antinuclear activists, some of whom have been protesting Shoreham since construction plans were announced in 1966, had the most reason to be pleased. The closing would be a precedent-setting first. More than 100 nuclear plants have been abandoned in various stages of development, but Shoreham would be the nation's first completed station to be shut down. Still, it may be months before the settlement is concluded; the plan must be approved by several state agencies and ratified by county and state legislatures. If the deal becomes public policy, the state hopes to dismantle the plant. But that may be easier said than done: the United States has no facilities for disposing of Shoreham's highly radioactive spent fuel and reactor parts.

Eloise Salholz with Peter McKillop in New York and bureau reports
The Mail

Heat Waves

Congratulations for publishing a courageous, straightforward account of the greenhouse effect and other man-made global perils (SPECIAL REPORT, July 11). I pray your message will reach those who profit from environmental devastation, those who mutter the word "environmentalist" with disgust—and the man who will be the next U.S. president.

Carol H. Milton
Houston, Texas

... ... ...

After reading your special report on the environment, I couldn't help envisioning a future visitor from another planet picking up and dusting off the yellowed pages of an old NEWSWEEK and saying to himself: "Aha, I think I've found something here; they must have known of their impending doom! Why didn't they do something?"

Star Elton
New Albany, Ind.

... ... ...

If this story does not awaken people to the need for fundamental changes, what will? Our economy seems to be based on buying, using and discarding as rapidly as possible. While the United States has less than 5 percent of the world's population, we produce one-fourth of its carbon dioxide and one-fifth of its sulfur dioxide. For global survival, we must end our materialistic, hedonistic lifestyle.

Richard H. Schwartz
Staten Island, N.Y.

... ... ...

It is clear that the widespread deforestation practiced by Third World nations saddled with huge debt burdens is wreaking havoc on the world's ecosystem. The Tropical Forest Protection Act (H.R. 3010), which I have introduced, calls for the World Bank and other multinational lending institutions to tie future lending to forest-conservation efforts and, where necessary, to suspend payments in exchange for protecting forests from development. This legislation has been endorsed by leading environmental groups.

John Porter
Member of Congress from Illinois
Washington, D.C.

... ... ...

It would appear that the earth, in its infinite wisdom gleaned from several billion years of existence, is starting to correct the problems our unbridled population growth has caused. Instead of hoping for a technological quick fix, we should begin to reverse the damage by instituting a world-wide, mandatory hundred-year program to lower the human population by half. Difficult and objectionable as this may sound, it is far more sensible and humane than what's in store for us if we continue on our present course.

Roger Holley
San Diego, Calif.

... ... ...

Isn't it ironic that the politicians and scientists blaming fossil fuels for the greenhouse effect are some of the same ones who, in the past, condemned the use of nuclear power? The environmentalists will have to swallow their rhetoric and accept the fact that no commercially available energy source is perfect. The source with the fewest problems, nuclear power, will have to be the bridge between the imperfect present and the much better future of fusion power in the mid-21st century.

Michael J. McClary
Anaheim, Calif.

AIDS Activists

I was delighted to find that ACT UP had finally made the pages of NEWSWEEK (NATIONAL AFFAIRS, June 6), but it angered and confused me to see us portrayed as just a group of rowdies staging colorful street theater. As a person with AIDS who has invested hard work and scant resources in ACT UP, I am trying to get the full story out, because by doing so I may save lives—including my own.

G. Steven Rose
Boston, Mass.

... ... ...

With human life at stake, spokesman Thomas Brandt's assertion that members of the presidential commission on AIDS have been "personally offended" by ACT UP's tactics is not even remotely relevant. ACT UP shouts a message about government funding for AIDS research that others have only whispered: stop putting your morality where your money should be. AIDS kills. Isn't it time to focus on eliminating this disease, not on which minority groups its victims belong to?

Katherine R. Hedrich
Chicago, Ill.

... ... ...

From Jan. 1 to June 1, 1988, 3,605 people died of AIDS (one every hour), and 12,386 new cases were reported (one every 17 minutes). Yet hundreds of potentially helpful drugs are languishing in limbo while the Food and Drug Administration and the National Institutes of Health—despite their many promises and protestations to the contrary—fail to streamline their testing procedures, which can take up to eight or nine years to complete. Considering the urgency of the AIDS crisis, this inaction is appalling.

Stephen Spinella
New York, N.Y.

TV Guidance

In "The Ms. Fixit of Kidvid" (TELEVISION, May 30), you point out that during the Reagan administration the Federal Communications Commission rescinded its children's-television guidelines. Then, you say, "into the void surged" such "cartoon superheroes" as He-Man and Captain Power. The fact is that "He-Man and the Masters of the Universe," based on Mattel's popular character, began running before deregulation and fully complied with all FCC guidelines at that time. As for Captain Power, he is not a cartoon but a live human being. Finally, I can assure you that we at Mattel take the issues Peggy Charren raises as seriously as we take responsibility to be a positive part of children's lives.

William Semos
Vice President, Corporate Affairs
Mattel, Inc.
Hawthorne, Calif.

Debating Day Care

Robert J. Samuelson says he has a daughter in child care (June 27), and no doubt he feels comfortable about the quality of the care she can afford. But what about the single mother who makes just over the poverty level? She has to take what she can afford. Inexpensive child care, without subsidies, means staff without training—people who could make more working at a fast-food franchise. We all know learning begins at birth, not at the age of five, when tax dollars begin to pay for education. Enough. Let's invest in our children during...
NEWS ADVISORY

PROTESTORS TO RING CITY HALL WITH BEDSHEETS,
DEMAND MORE FUNDS FOR AIDS EPIDEMIC

HUNDREDS OF DEMONSTRATORS CARRYING BEDSHEETS WILL MARCH TO CITY HALL ON MONDAY, JUNE 13, AT 5:30 P.M. TO DEMAND MORE FUNDS FOR DEALING WITH THE AIDS EPIDEMIC IN NEXT YEAR'S NEW YORK CITY BUDGET.

CHARGING THAT MAYOR KOCH'S PROPOSED BUDGET FAILS TO CARRY OUT HIS PLEDGE TO PROVIDE A BED FOR EVERY PERSON WITH AIDS, AND ALLOCATES INSUFFICIENT FUNDS FOR AIDS EDUCATION AND TREATMENT, PROTESTORS WILL MASS AT FOLEY SQUARE AT 4:30 P.M. AND MARCH TO CITY HALL. DEMONSTRATION AT CITY HALL MAY INCLUDE CIVIL DISOBEDIENCE.

PROTEST IS SPONSORED BY ACT UP (AIDS COALITION TO UNLEASH POWER), A NON-PARTISAN GROUP COMMITTED TO DIRECT ACTION TO END THE AIDS CRISIS.

For more information: Ron Goldberg (212) 246-2879
Andrew Miller (212) 662-9330
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<tr>
<th>CONTACT</th>
<th>HOME PHONE</th>
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<td>* Jason Heffner</td>
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<td>David Barr</td>
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<td>Joan Gibbs</td>
<td>212-614-6840 (eve)</td>
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<td>Bill Dobbs</td>
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<td>Jill Harris</td>
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<td>* Russell Pritchard</td>
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<td>Jean Elizabeth Glass</td>
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<td>* Victor Mendola</td>
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<td>Robert Garcia</td>
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<td>Robin Crutchfield</td>
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<td>Vincent Gagliostro</td>
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<td>* Richard Elovich</td>
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<td>David Z. Kirchenbaum</td>
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<td>Iris Long</td>
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<td>Bob Lederer</td>
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<td>Mark Harrington</td>
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<td>Rachel Lurie</td>
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<td>212-349-8155</td>
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<td>Maria Maggenti</td>
<td>212-941-7506</td>
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<tr>
<td>Ilith Rosenblum</td>
<td>718-409-8270</td>
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* CO-ORDINATING COMMITTEE MEMBER

SILENCE=DEATH

CONTACT SHEET UPDATES: Call Tim Smith (h) 212-243-1147 or (w) 952-1700
ACT UP ACTIVITIES
For the week of February 20, 1989

TUESDAY, FEBRUARY 21

Fundraising Committee, 7:00 p.m.
The Center, 208 West 13th Street

Caucus to House Homeless PWA's Now, 7:30 p.m.
27 Grove Street #1B

Coordinating Committee Meeting, 8:00 p.m.
The Center, 208 West 13th Street

WEDNESDAY, FEBRUARY 22

Lasagna Committee, 6:30 - 8:00 p.m.
Pentacle Space, 104 Franklin, 5th
(1RT #1 - Franklin Street Stop)

Treatment & Data Committee, 8:00 p.m.
Including Third Party Reimbursement
Pentacle Space, 104 Franklin, 5th

THURSDAY, FEBRUARY 23

Montreal AIDS Conference Committee, 7:30 p.m.
43 East 19th Street, 2nd Floor (Spiers), 212-254-4996

Media Committee, 8:00 p.m.
160 East 3rd Street #5-J (Signorile), 212-979-7529

FRIDAY, FEBRUARY 24

Actions Committee, 8:00 p.m.
The Center, 208 West 13th Street

SATURDAY, FEBRUARY 25

Montreal AIDS Conference Committee, 7:30 p.m.
43 East 19th Street, 2nd Floor (Spiers), 212-254-4996

MONDAY, FEBRUARY 27

ACT UP General Meeting, 7:30 p.m.
The Center, 208 West 13th Street

New Member Orientation is presented the first Thursday of every month at The Center.
At-Large Member meeting is the third Thursday of every month at The Center.
May 4, 1989

Dear John:

I just wanted to dash off a note accompanying our text, AIDS DRUGS NOW. I got the latest issue of ATN today, and was very excited to read your article "The Drug-Trials Debacle ..." It seems our thinking is independently converging in many of the same conclusions and directions.

I think it is desirable for the AIDS community to unveil a new, comprehensive AIDS research agenda for the next 2 years at the Montreal conference.

After Tuesday's hearing at the Lasagna Committee, it is clearer than ever that the Federal research bureaucracy and the academic-industrial axis has no idea whatsoever about how to expeditiously move to end the epidemic. Revenue streams are flowing, and they have more of an investment in keeping them flowing than in solving the crisis. Yet at the same time they are acutely aware of their failure thus far.

There is a vacuum at the very heart of the Federal AIDS Research establishment. We should move in and seize control with a compelling and practical agenda that accords as much attention to the OIs and the HIV itself.

Please write or call when you have had a chance to review the enclosed.

Congratulations on your latest issue.

Yours truly,

Mark Harrington

611 e. 11th st. 7A
NY NY 10009

212 353-8430
As most ACTUP members are aware, a couple of incidents last week are generating discussion and concern among the group. We are writing to provide ACTUP members with an outline of what has happened, and to provide the group with some tools to help members effectively respond to further incidents of like kind.

In the first incident on Monday, September 26th, in the course of a march through the West Village streets, marchers and police clashed, leading to two arrests, with felony charges of assaulting a police officer lodged against one of our members. The police used excessive force, and our members, in trying to support each other, were physically abused and arrested. One member spent two days in jail, where he received verbal and emotional abuse.

In the other incident, on Wednesday, September 28th, a special division of the police department showed up at a member's home at six in the morning to ask questions and search.

We are concerned about the level of anxiety being generated in the wake of this incident. We deserve to be angry about how the police have been treating us. But more important is how we process this anger most productively for ACTUP.

We now know that we are not immune from police efforts to intimidate and coerce us. Nevertheless, we can take care of ourselves and each other when the police take action against us. First, we stay calm. This does not mean that we cannot become angry or frightened. But when anger and fear turn to thoughtless rage or panic, we lose our ability to stay in control of the situation. By knowing what to do in advance of any situation, we feel in control, and stay calm. If we go out with adequate information and a plan of action, our clear thoughts and centered energy provide us with a strong, united and cohesive group ready to effectively get its agenda fulfilled. If each of us responds to these tactics in the same way by following the guidelines on the back side of this sheet, we know we are not alone (and so do the police) because we are following a unified plan. If we know our rights and stick together, the police will realize that their efforts to intimidate us have failed.

Finally, we are not trying to dictate to any ACTUP member how to proceed. We are concerned that each member reflect on any action that she or he takes, whether participating in a demonstration or responding to police investigations. We should be aware of how that action relates to the group. At our best, all our actions support ACTUP and its members, empowering the group. Let's be clear before we act that our actions give each other support.

October 3, 1988

Bill Dobbs
Kayeton Kurowski
Mike Spiegel
Mickey Wheatley
David Barr

"I hear you knockin', but you can't come in." — Little Richard
KNOW YOUR RIGHTS WHEN THE COPS OR FBI COME
KNOCKING AT YOUR DOOR, OR WANT TO ASK YOU QUESTIONS:

1. You do not have to talk to the police or FBI or any other investigators. You do not have to talk to them whether they come to your house, on the street, if you’ve been arrested, or even if you are in jail. Only a court or grand jury has legal authority to compel testimony.

2. You don’t have to let the police or FBI into your home or office unless they show you an arrest or search warrant which authorizes them to enter that specific place.

3. If they do present a warrant, you do not have to tell them anything other than your name and address. You have a right to observe what they do.

4. Make written notes, including the agents’ names, agency, and badge numbers. Try to have other people present as witnesses, and have them make written notes, too.

5. Anything you do say to any law enforcement officer may be used against you and other people.

6. If you do give the FBI or police information, it may mean that you will have to testify to the same information at a trial or before a grand jury.

7. Lying to an FBI agent or other federal investigator is a crime.

8. The best advice, if the FBI or police try to question you or to enter your home or office without a warrant, is to JUST SAY NO! Law enforcement agents have a job to do, and they are highly skilled at it. Attempting to "outwit" them is very risky. You can never tell how a seemingly harmless bit of information can help them hurt you or another ACT UP member.

9. The investigators may threaten you with a grand jury subpoena if you don’t give them information. But you may get one anyway, and anything you’ve already told them will be the basis for more detailed questioning under oath.

10. They may try to threaten or intimidate you by pretending to have information about you ("We know what you’ve been doing, but if you cooperate it will be all right."). If you are concerned about this, tell them you will consider talking to them with your lawyer present.

11. If you are nervous about simply refusing to talk, you may find it easier to tell them to contact your lawyer. Once a lawyer is involved, the agents usually pull back since they have lost their power to intimidate. If you are taken into police custody, once you request an attorney, they must cease questioning until you lawyer is present. But remember, you don’t have to answer their questions, even if they keep asking.

ACT UP lawyers:

David Barr 212/995-8585 (w. day)
212/995-8969 (w. eve)
212/933-9740 (h.)

Joan Gibbs 212/614-6464 (w. day)
212/614-6420 (w. eve)

Mike Spiegel 212/838-3300 ext. 425 (w. day)
212/781-7884 (h.)

Bill Dobbs 212/966-1091 (all hours)
AIDS ACTIVISTS TO PROTEST
REAGAN AND BUSH AT MIDTOWN FUNDRAISER

On Monday, September 26, at 12:00 noon, The AIDS Coalition To Unleash Power (ACT UP) will stage a protest outside the Waldorf-Astoria Hotel (Park Avenue between 49th and 50th Streets), where a Republican Party fundraising luncheon will be held for the George Bush For President Campaign. Activists will confront President Reagan and Vice President and Republican presidential candidate George Bush with the names and photographs of friends, lovers and family members who have died from AIDS during the Reagan administration.

The demonstration will protest: The Reagan administration's grossly inadequate response to the AIDS crisis; the lack of meaningful dialogue on AIDS from the presidential candidates; and George Bush's shameful ignorance of the AIDS crisis. When AIDS was raised this spring in a candidates' debate, Bush said:

"There are lots going on, on AIDS, and to hear them wringing their hands on everything being wrong with this country,

I'm sorry, I'm all depressed.

I want to switch over to see 'Jake and the Fat Man' on CBS."

Contact:
Andrew Miller
(212) 662-9330
Last August ACT UP sent out this important letter to raise funds. Now ACT UP needs help again, and we had a few letters left over ... dated August 1988.

Rather than waste those -- and reprint a new letter with updated information -- we decided that supporters of ACT UP would rather we not waste paper and money.

That's why this letter is dated August, and that's why we strongly hope you'll be able to start the new year with a generous gift to ACT UP.
Dear Harvey Fierstein,

I want to fight back with ACT UP. Here's my gift to help get our message heard—on the streets and inside the corridors of power.

☐ $100 *  ☐ $75  ☐ $50  ☐ $35
☐ $250  ☐ $500  ☐ $1,000  ☐ Other: $ __________

* ACT UP is important
Please consider making an extra large contribution

CONTRIBUTION $ _______
MERCHANDISE TOTAL (from reverse) $ _______
TOTAL ENCLOSED $ _______

10394
JOHN S. JAMES
P O BOX 411256
SAN FRANCISCO, CA 94141

Please make your check payable to ACT UP and mail in the enclosed pre-addressed envelope to Harvey Fierstein, c/o ACT UP, PO Box 261, 70-A Greenwich Avenue, New York, New York 10011.
I want to help spread the word about ACT UP. Please send me the following merchandise (Specify quantities; $15 minimum order)

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<th>Item</th>
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Total Donation For Merchandise Items

(T-Shirts 100% Cotton / Sweatshirts 50% Cotton, 50% Polyester)

Please send information about ACT UP to:

________________________________________________________________________
________________________________________________________________________

SILENCE=DEATH posters are 24 x 29", AIDSGATE posters are 22 x 34" printed on high-quality glossy paper stock and sent to you in heavy mailing tubes suitable for framing or for appropriate bulletin boards anywhere people need to see them.

ACT UP T-Shirts have already become hot collector’s items. Professionally designed and manufactured, these attractive 100% cotton T-Shirts and 50% cotton, 50% polyester sweatshirts have sold out at rallies and marches all year long. Order yours today and let the world know you’re an ACT UP supporter.

Buy ACT UP buttons to wear yourself and give to friends. An excellent “first step” to raise the political consciousness of everyone who sees them.
Up to now, ACT UP has paid for its activities with a few small fund-raisers and the sale of t-shirts and buttons.

But they have much more to do. They want to establish a Bail Fund ... increase their lobbying efforts ... organize a national petition ... buy ads in newspapers ... anything they can to force our issues into the public's awareness.

And they want to organize even more demonstrations -- all over the nation, if possible. Already, other ACT UP groups have formed in New Jersey, Philadelphia, Chicago, Boston, Ft. Lauderdale, San Diego, San Francisco, Los Angeles and Toronto.

ACT UP now has more than 1,500 members. Many contribute dozens of hours each week -- at planning sessions, demonstrations, fund-raising events -- in addition to ACT UP's weekly meetings each Monday night at 7:30 at the Lesbian and Gay Community Services Center on 13th Street in Greenwich Village. (Come join a meeting!)

Will you join ACT UP also, in spirit if not in body?

They need your support, and that's why I'm asking you to take two simple steps:

First: Support ACT UP and send the largest contribution you possibly can. Every dollar you give makes their voice a little bit louder. Plus - a portion of your gift will be given to other AIDS activist groups around the country!

Second: Get loud yourself. Join an ACT UP demonstration. Organize an ACT UP group in your area. Buy a t-shirt and wear it. Buy a bunch of buttons and give them as presents to your friends.

Get loud about AIDS.

Please -- none of us can afford not to do everything in our power to save the lives of those we love or to fight for our own lives and future.

Neither you nor I can stop AIDS alone. No one can. But our voices together -- yours and mine and ACT UP's -- can only bring us closer, faster, to a cure.

I hope very much to hear from you soon.

Sincerely,

Harvey Fierstein

PS. You can show your support right away by ordering your "SILENCE = DEATH" or "AIDSGATE" t-shirts, buttons, and posters with the order card I've enclosed. Sorry, they do not come free with a contribution.
Later, ACT UP went to Washington, D.C. to join with other activists in a protest at the White House and the opening of the Third International AIDS Conference. The action garnered extensive international media attention when the police put on yellow rubber gloves to arrest 64 people. Our message of frustration became the theme of the conference.

And when Northwest Orient Airlines refused to accept passengers with AIDS, ACT UP picketed their office, clogged their switchboards and booked hundreds of bogus reservations. After two weeks, they modified their decision.

ACT UP demonstrated at New York's Memorial Sloan-Kettering Hospital -- an official NIH treatment center -- with an impressive four day, 24 hour picket. They protested the fact that though Congress had appropriated funds to put 12,000 people on clinical trials, the NIH had fewer than 1,000 actually enrolled in them.

In a matter of weeks, the NIH doubled the number of patients accepted into their protocols, and ABC's Nightline was prompted to devote a full program to spotlight the inadequacies of the NIH's treatment centers.

ACT UP's most impressive victory to date has been its influence on President Reagan's AIDS Commission. They were there when the Commission met for the first time in Washington. They had four members testifying inside while a large demonstration was held outside. Again, an ACT UP demonstration received international media coverage.

But they didn't stop there. Whenever Reagan's Commission met, whether in Washington or Miami, ACT UP was there lobbying for our concerns -- more studies of promising drugs and quicker release of those drugs.

ACT UP's efforts paid off. Admiral James D. Watkins, the Commission's new chief, issued a preliminary report in December outlining the issues they would be looking at. "The deadly nature of AIDS demands new and streamlined approaches to drug development," Watkins said. "We can no longer wait on that issue; we are putting it up front in the Commission's work." Significantly, there was no mention of HIV antibody testing.

There are times -- and I believe this is one of them -- when a community has no choice left but to demonstrate to make its voice heard. Quite frankly, I am afraid of what might happen if we don't protest, if we don't take to the streets, if we don't force the government to hear our plea . . .

With this letter, I'm hoping that you hear the plea expressed in our motto "SILENCE = DEATH". ACT UP needs you to join them.

(over, please)
***There is money available to test those drugs and treatments, but Federal policy-makers have chosen not to spend it. For many, the priority is to find a vaccine for those not infected rather than a cure for those who are.

***The public's focus has been skillfully diverted to side issues -- like HIV antibody testing -- that falsely convince the average American something is being done about AIDS.

***Meanwhile, the Reagan Administration has publicly opposed any legislation to safeguard the basic rights of people with AIDS. The Secretary of Health and Human Services, Otis Bowen, shocked Congress when he testified that the Administration saw no evidence of discrimination towards People with AIDS.

The facts demand our cries of outrage. AIDS is too important to be quiet about!

The "SILENCE = DEATH" logo on the envelope symbolizes this message. Our community's silence contributes to our own possible genocide.

Think about that. And about what you can do to stop the silence.

That's why I'm writing to you.

I want to tell you about an important new grassroots organization -- ACT UP -- that has already made a vital difference in the fight against AIDS.

ACT UP stands for the AIDS Coalition To Unleash Power.

In its first nine months, ACT UP has organized more than a dozen public demonstrations.

At their first demonstration -- on Wall Street -- they hung the Commissioner of the Food and Drug Administration (FDA), Dr. Frank Young, in effigy. Seventeen ACT UP members were arrested. Media everywhere reported this action.

To some this might seem extreme. But let me tell you the result: Within one week the FDA announced rules for swifter drug release. The National Institutes of Health (NIH) agreed and released into experimentation two of the drugs that ACT UP had been fighting for.

On the CBS Evening News, Dan Rather specifically gave ACT UP the credit for these accomplishments.

(next page, please)
Dear Friend,

The dedication to my play "Safe Sex" read as follows:

"To my little Christopher. You will live to
celebrate life again. Trust me on this one."

It was a promise I could not keep.

Within ten months of my writing that, Christopher was
dead. At the time of his death he was almost totally paralyzed,
incontinent, demented, and in great pain. He was twenty-six
years old and had AIDS.

Christopher was one of four members of the "Torch Song
Trilogy" company to have died of AIDS. We lost another five people
from the companies of "La Cage Aux Folles". And my personal address
book looks more like a calendar: names crossed off like so many days
passed and gone.

Now, however, is not the time to grieve. There's too much
work to be done. The greatest tribute we can pay our fallen brothers
and sisters is to insure their place in history as the last to have
died because of AIDS.

I'm writing to you now because I'm angry. I'm angry
because of our government's reckless (perhaps
intentional?) disregard for the people primarily
affected by this disease: gay men and IV drug users.

Because of AIDS thousands of lives have been lost, millions
more are threatened and all we have experienced from the White House
is a blatant disinterest. The disgusting, amoral attitude of the
Reagan Administration has drawn a battle line between "Low Risk" and
"High Risk" America. Must we now declare war to be heard?

Let's examine the facts:

***There are drugs and treatments that can prolong our
lives -- many people with AIDS obtain them illegally.
But government red tape keeps them from the majority
of people who need them.

(over, please)
John - I left a message on Emily's recorder that she could make the 400 copies at her end, presuming it was for an ACT-UP meeting activity — suggested she call me back on Monday.

Act-Up New York
496-A Hudson Street, Suite G-4
NYC 10014

Attn: Emily Gordon

Phonememo

TO
John

FROM
Emily Gordon

DATE
5-6

TIME
AM PM

MESSAGE
#77 — "best damn thing I've ever read." wanted 400 copies

ACT-UP New York
(212) 690-1242

Signed
Tim

400 shipped 5-9-89

5-6-89
Name ___________________________________________________________________________________
Organization __________________________________________________________________________
Address _________________________________________________________________________________
City, State, Zip _________________________________________________________________________

Thank you for your interest in AIDS Treatment News. Please check the appropriate categories below and enter the total dollar amount. Return invoice to our San Francisco address with payment to "ATN Publications."

ONE-YEAR SUBSCRIPTION (26 biweekly issues):

___ Professional/Institutional Rate: $100.
___ Regular Individual Rate: $100.
___ Reduced Rate (people who are HIV+ and who cannot afford regular rate): $30.
___ International Air Mail (outside N. America): add $20.

SIX-MONTH SUBSCRIPTION (13 biweekly issues):

___ Professional/Institutional Rate: $55.
___ Regular Individual Rate: $55.
___ Reduced Rate (people who are HIV+ and who cannot afford regular rate): $16.
___ International Air Mail (outside N. America): add $10.

BACK ISSUES (1-50 with index and 3-hole format for use in loose-leaf binder):

___ Professional/Institutional Rate: $75.
___ Regular Individual Rate: $75.
___ Reduced Rate (people who are HIV+ and who cannot afford regular rate): $18.
___ International Air Mail (outside N. America): add $18.

$ ___________ .00 TOTAL ENCLOSED (Payment to "ATN Publications.") *

* Outside the USA, send US$ funds by any of the following: international postal money orders, US-bank checks, US-bank drafts, or travelers checks.

SUBSCRIPTIONS BEGIN IMMEDIATELY UPON RECEIPT OF PAYMENT.
Mea Culpa to Gays

The publishing world is abuzz over Malcolm Forbes' extraordinary personal apology to the gay community in the issue of Forbes magazine due to hit the stands this week. In it, Forbes expresses his regrets that the magazine's June 26 issue included an article — "Straight Talk About AIDS" — that accuses gays of exaggerating the severity of the AIDS crisis in order to increase their political clout. Forbes denounces the article's premise as "asinine," and explains that "I was traveling, I didn't see it in time to kill it." The Forbes letter of apology on Page 20 is followed by a 13-point rebuttal of the article by the AIDS Coalition to Unleash Power, which demonstrated outside the magazine's Fifth Avenue headquarters last Tuesday. "I wish everything could be resolved so beautifully," said ACT UP's Greg Lugliani, who participated in the demonstration. "Mr. Forbes invited us up to his office personally when he saw us outside and gave us nearly two hours to write our piece. He was extremely gracious and apologetic." It's the least you'd expect from a guy who dates noted AIDS activist Elizabeth Taylor.
June 30, 1989

Mr. Thomas McAn
VP, Corporate Communications
Bristol-Myers Co.
345 Park Ave.
New York NY 10022

Dear Mr. McAn:

ACT UP found our meeting with Bristol-Myers last Friday unsatisfactory. Bristol-Myers seemed unaware of new developments in Federal research and regulatory AIDS policy.

On the very day of our meeting, NIAID Director Dr. Anthony Fauci addressed an HIV conference in San Francisco, and endorsed the idea of a parallel track for trials of drugs like ddI. Please refer to the enclosed articles.

Dr. Birnbaum said the phase II ddI trials are not yet designed. Yet on June 19, at the AIDS Program Advisory Committee (APAC) meeting in Bethesda, NIAID's Dr. Dan Hoth showed a slide of the inclusion and exclusion criteria for some of those trials. Furthermore, Birnbaum admitted the trials of the AZT-intolerant would involve between 300 and 600 subjects. This suggests that, while some final details remain to be worked out, ddI protocols are substantially complete.

More seriously, Dr. Birnbaum claimed FDA still required statistically significant differences in survival to prove antiretroviral efficacy. This is wrong. In April, at FDA's pilot skills workshop for community-based research groups, and in June in Montreal, FDA's Dr. Ellen Cooper made it clear that death vs. survival were no longer desirable as endpoints for antiretroviral efficacy trials.

The FDA will accept, and the AIDS community demands, endpoints well short of death. These might involve a combination of clinical events (weight loss or gain, decreased incidence of ARC symptoms or opportunistic infections) with those surrogate markers that have shown the most prognostic value (p24 antigenemia, Beta-2 microglobulinemia, absolute CD4 count) to prove efficacy.
Dr. Birnbaum also reported that principal investigators, when asked whether ddl should be made available on a parallel track to those ineligible for controlled trials, said this would impede enrollment in the controlled trials. Their assertion is untrue, and reveals the legacy of mutual mistrust between researchers and HIV-infected people which has delayed AIDS research.

No trials of anti-HIV agents will succeed without the cooperation of the AIDS community. There are two prerequisites for obtaining this cooperation: the speed of the trials and the trust of the community.

If controlled Phase II trials and parallel track trials are not designed, conducted and completed with all due speed, the community will be forced to seek other avenues for access to new and promising anti-HIV treatments. The development of an underground network of pharmacologically bioequivalent ddl is not a possibility, it is a certainty, if Bristol-Myers' trials are not underway soon. Principal investigators should be aware that such a network, rather than a parallel track which gathered evaluable data for marketing approval, is the real threat to the integrity of Bristol-Myers' trials.

Compliance in controlled clinical trials is attainable only if potential subjects trust that the sponsor and investigators are truly concerned with the subjects' well-being.

If the trust of the community is not obtained, and people are needlessly excluded from participation in crucial clinical research, Bristol-Myers' trials will be delayed by slow enrollment and the resulting data confounded by subjects taking concomitant medications without telling investigators.

But if Bristol-Myers develops comprehensive, quickly-implemented, humane and scientifically valid protocols which the community can support, results will be expedited and the hoped-for marketing approval hastened. This should be the endpoint which we work for together.

ACT UP looks forward to discussing these matters with Bristol-Myers in the next two weeks. I will call later today to schedule our next meeting.

Yours truly,

Mark Harrington
Treatment + Data Committee
ACT UP/New York
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 VIP’s - 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 Sonnabend, 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 Eigo 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.
There were hundreds of speeches, posters and abstracts about new treatment developments. Treatment + Data has not had time to fully absorb this new information. 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 start 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 immunoadhesin) 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, streptomycin 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 Metroka, 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.

More updates will follow. ACT UP is scheduling meetings with Bristol-Myers (DDI, Peptide T), Ortho (EPO), Pfizer (Fluconazole) and with FDA and NIAID to discuss parallel trials and their response to the ACT UP research agenda.
Not the Last Dance

by KEVIN KOFFLER

Riding up in the elevator to Donna Summer's suite in West Hollywood's Bel Age Hotel, I feel a flood of memories come rushing over me. I remember the exhilaration of experiencing "Hot Stuff" my first time at a gay disco in New York City. I recall heated lovemaking to "Love to Love You, Baby" on hot, sweaty summer nights in my West Village fifth-floor walk-up. I remember early mornings at the Pavilion in the Pines on Fire Island, when "Last Dance" was never the last dance.

But then I remember that since becoming a born-again Christian, Summer has supposedly turned her back on gay people, the people who created her and made her into a star—their star. The reports of Summer saying, "God created Adam and Eve, not Adam and Steve," and "I have seen the evils of homosexuality; AIDS is the result of your sins," keep playing over and over in my head like a bad movie.

I'm willing to give people the benefit of the doubt, however. I'm a journalist; I'm supposed to be impartial.

I step out onto the hotel's sixth floor and see Summer standing on her balcony, staring off into the sprawling landscape that is Los Angeles. She looks incredibly peaceful.

I knock on her door, and Summer lets me in. She's still kind of goofy, in a cute-little-kid kind of way, dressed in a black shirt, skirt, and Lycra leggings, with a big black bowler hat. She pours me a glass of Evian and refills her glass of soda, and we sit down in the living room of her suite.

I bite my tongue and suppress the desire to blurt out, "So, I hear you hate gay people and you wish we'd all die of AIDS," opting instead to discuss her new album, Another Place and Time, her first for Atlantic Records. I try to remain impartial, but perhaps at this point I am subconsciously weaving her into my web before going in for the kill.

Summer's new record is her first world-wide hit in over five years. "This Time I Know It's for Real" is her first U.S. Top 40 hit in as long. The album was produced, arranged, and written by the team of Stock-Aitken-Waterman, which is also responsible for the success of Kylie Minogue and Rick Astley (who recently fired the team as well as his manager—career suicide, according to Summer).

"It's a very '80s-sounding record," says Summer, "but it's the closest thing to my big hits with Giorgio [Moroder]. Stock-Aitken-
Waterman probably sound closer to Giorgio, in general, than anyone else has since I was with him."

Summer collaborated as a writer on only two of the album's ten tracks but explains, "I didn't really have less creative control on this record; anywhere they wrote without me was only because I told them to write the song. I'd say, 'Look, I want to go to a polo match; you write,' and they did. They didn't say, 'You can write only this much, and we're going to do the rest.' It wasn't anything like that.

"They are much better than people give them credit for. Their desire is to create a Motown for the '90s — discovering new talent and developing that. I'm the exception at this point.

"People's reaction to the new record is really good. I'm surprised almost. I like it, but you never know what's going to happen until you get it out there. Being with Atlantic is like running into an oasis. There's plenty of water, food, and excitement. It's great, and it's been an emotional thrust."

"But," I interrupt, "if the sound you and Giorgio created was so successful and magical, why did you leave him in the dust when you recorded your second album for Geffen Records? And speaking of Geffen, what happened to your deal there? What came down?"

"The record company wanted me to make different kinds of songs and records," sighs Summer. "They didn't think the old way was working. They thought my time with Giorgio had run out. The Wanderer album did very well, but when Giorgio and I went in to record the next album, they stopped us midway, because they didn't like it. They used one of the songs, "Romeo," on the Flashdance album, but they said the rest of the songs wouldn't make it. That's when they made me switch producers.

"Giorgio was my mentor, my guide. He was like — well, I wouldn't dare call him my father, because he would kill me — but he was like my father in the business. All of a sudden, they were taking away everything that was true and dear to me and putting me with people I didn't know.

"As for the record company, it just didn't work out," Summer continues. "It was one of those situations where they didn't have the confidence they needed to have in me. David [Geffen] desperately wanted to sign me as his first act, so he did. I love David. I used to go to his house to write songs. I don't know at what point things started going awry, but they did.

"It might have happened when he got into making Cats and then movies and just got interested in other things. When I joined his company, he made all kinds of promises — 'I'm going to put you in the movies, blah, blah, blah.' He never did, and it became apparent to me that I had made a major mistake.

"But that's OK. I had six or seven years to sit home with my kids and to hang out on my ranch." Summer's ranch is situated between Los Angeles and Santa Barbara, where she raises "horses, cows, sheep, ducks, turkeys, and pokers." She says her husband butchers a cow every six months; they give half the meat away and keep the rest for the family (although Summer says she can't eat something she's seen alive and walking around).

"I learned that everything that brings you success does not bring you joy. It was a hard lesson to learn, because when I was young, I equated success with happiness. For me, success means work. Sure, people are screaming your name for a week, a month, or a year — however long it is — but the reality is that they are going to forget it as soon as the next hit record is released by someone else. Then they are going to be yelling that name.

"You've got to maintain your level of self-esteem through everything. You are who you are, and nobody will ever be able to take that from you if you don't let them," she adds.

"Sometimes I look at people and I see where I used to be, and I think, That person has more value than they're doing with their life right now. They don't think they do well, but when they find out they have more value, it's going to change them. It changed me."

Summer says her life used to be incredibly chaotic, but now it has become normal. "I was either going to OD on some kind of medication, or I kept having these flashes of doing something crazy - like taking too many of the pills I had to take because I was always so depressed.

"I needed to take mood elevators to balance me out, but they would make me manic and crazy. Then I'd have to take Valium to bring myself back down. I was just all over the place. I went through years of walking into rooms of people, unable to remember anyone's name because I was so out of it.

"It's a miracle I was able to get out on stage and remember the words to my songs. A lot of times I couldn't. Certain songs were difficult for me to remember. I'd have mental blocks to them, so I'd write down the words and put them on the stage floor. When I was drugged out, I'd still forget them. Someone in the band would have to hiss, 'It's over there,' and then I'd find them — sometimes."

When Summer reaffirmed her faith in God, she says, she had an immediate deliverance from her addiction to drugs. "It was instant!" she exclaims, clapping her hands to accentuate her point. "It was quicker than me saying it to you. I was immediately normal, and I hadn't felt that way in several years. It's something you can know only if you've experienced it. It's nothing I can explain to you.

"I know God is real. Anyone can tell you whatever they like — that God doesn't exist, you are God, I am God. Baloney! I cannot make a tree; I don't have that power. I can't stop a wave on the beach. I know there is a force outside of myself that is guiding my life. It's inside of me now too, because I have accepted it there. I have a lot of faith.

"Being a Christian," she continues, "doesn't make me perfect. I have chosen to live my life in a way that will be an asset to others as well as to my children and myself. If someone wants to misconstrue that with all the baloney about Christianity and people who profess to be Christian but are not, that's their problem. Christianity does not make you perfect; it's about asking God to hold you to the commitment to be perfect in a way."

— This seemed like the right time to ask Summer the most important questions of our interview: Does she hate gay people? Does she think homosexuality is a sin? Does she think AIDS is God's wrath against homosexuals? And did she ever make a public statement to that effect?

— "I did not make that statement," Summer says angrily. "Eight years ago, I made a reference to AIDS. What I supposedly said I did not say, and my reference to AIDS was really an innocent reference.

— "At the time, I thought AIDS was a herpes pimple, like you get on your mouth. I certainly didn't have any idea what it really was, and certainly if I had, in my heart I would not wish AIDS on anyone. I'm not that kind of person. It's one of the most horrifying diseases around. I don't think they're doing enough for it.

— "I've lost a lot of friends who have died of AIDS," continues Summer, tears welling in her eyes. "I'm hurting as much as anyone else at the amount of people who are gone. Last year was an incredible year in terms of friends of mine who died — people who ran my first album, who were really close to me, beautiful guys, and I mean beautiful guys."
It is devastating.

"In the past two years, I've done several AIDS benefits, but I'm not going to do AIDS benefits to prove to someone that I'm not antigay. Some of the most creative people in this country are gay and have given great things. I have people in my family who are gay. I have people in my life, who have been in my life before any of this stuff went on, who are gay.

"A couple of the people I write with are gay, and they have been ever since I met them. What people want to do with their bodies is their personal preference. I'm not going to stand in judgment about what the Bible says about someone else's life. I've got things in my life I've got to clean up. What's in your life is your business.

"I never said, 'If you are gay, God hates you.' Come on, Be real. I don't understand that. Anybody who really knows me knows I wouldn't say that.

"I never started a war against gay people. It all started with one newspaper writer [Jim Feldman, in a 1983 review of Summer's post-born-again Atlantic City comeback concert, in the Village Voice]. I did not make those statements.... The guy who wrote it, I think he was angry at me for accepting God. But his attack wasn't on God; it was on me.

"I can't defend myself. People are just going to say, 'She can say anything now.' But if I wrote a vicious story about you and put it in the newspaper, I guarantee that you would run into it for the rest of your life. It's always going to be in the back of people's minds, whether you said it or not.

"It hurts. It makes me ache. I can't stand to talk about it because it hurts so bad. When I first started, they said I was a man—a transvestite. That too was a rumor. It passed.

"My songs are about people and their relationships to other people. Jesus said, 'Love thy neighbor'—whoever is next to you. [Christianity] says, 'First remove the log from your own eye, that you may remove the splinter from someone else's.'

"It's tough, but I know what my commitment to God has meant to me, and I know in my personal life it has saved me. I can't deny that. If I was asked to deny that, I'd have to deny everything else, because it's the only reason I'm alive.

"Only that spiritual connection brings you true happiness," she concludes. "It brings you to who you are, and it makes you realize you have importance whether other people recognize it or not. You know who you are. That's the most important thing."
Lesbian-gay parade was a form of protest, not a ‘fun’ affair

DID Ray Kerrison go to Fifth Avenue looking for the Easter Parade and find the annual Lesbian and Gay March instead (“Specter of AIDS stalks gay parade,” June 26)?

I am sure that New York City’s entire lesbian and gay community is feeling as strongly as I do a deep sense of responsibility for failing to make this year’s event “fun” for him. Aw, shucks.

For a little reality to seep in here. The Pride March is not an afternoon’s entertainment. It is a protest, a defiance of the silence and invisibility that lesbians and gays have been forced to live in throughout history.

It is a unified voice raised against the violence that is done to us in this society, whether it be the violence of neglect, ignorance, prejudice or hate. And every act of violence, from a person with AIDS denied prompt, adequate treatment, to a lesbian or gay man beaten to death by thugs who think they’re performing a public service, has its genesis in the type of thought that characterizes Kerrison’s article.

The moment of silence observed by the marchers was for the friends, family, loved ones and lovers we have lost to AIDS.

And they died, not as a result of a “homosexual lifestyle,” but because Kerrison and those like him in the government, in the FDA, in every agency who long ago should have embraced their responsibility to the victims, have instead allowed the official policy to remain “too little, too late” and through that policy have let thousands of men, women and children, gay and straight, die.

Lifestyle is not the enemy, AIDS is not the enemy; Kerrison, with all he represents, is the enemy. We know it, and so does he. Shame.

CYNTHIA K. BRENEMAN, Manhattan

As one of almost a quarter million participants in the Lesbian and Gay Pride celebration on Sunday, June 25, I must take exception to your June 26 coverage of the march.

The amount of space you devoted to a small handful of pathetically misinformed protestors was not only unnecessary but also biased and ultimately not newsworthy in light of the fact that hundreds of thousands of people — both gay and straight — participated in celebrating the 20th anniversary of Lesbian and Gay Pride and History.

JOHN HENNESSY, Brooklyn
Act Up: Bobby O'Malley spends his free time getting arrested with hundreds of his friends in ACT UP, the AIDS Coalition To Unleash Power. Get ready for 'The Fight Back Rap.' Pages 2-3

TV: Rick Ducommun Offers 'Piece of Mind,' on HBO. Page 5

BQEats: Italian and Special Specials at Lanterna, Astoria. III / 30
Making A Scene

Bobby O’Malley and a new generation of gay activists are having fun, causing trouble, fighting for survival

By Jonathan Mandell

OBBY O’MALLEY, a blond Boy Scout from Omaha, moved to New York four years ago and adjusted quickly to gay life. He waits tables in a starched white Nehru jacket at China Grill, works out five days a week at the Chelsea Gym, summers in Provincetown, gives a fabulous annual Halloween party; and right now is lying down in the middle of the street in front of City Hall, blocking traffic.

"Act up
Fight back
Fight AIDS
Act up"

Passive protest is our style but sometimes we must go to trial and this is how our goals are won.

O’Malley, 28 years old, wrote the "Fight Back Rap," and he leads the others when he chants it. He was an early member of ACT UP, the AIDS Coalition To Unleash Power, a group celebrating its second anniversary this sizzling spring morning doing what they do best.

On his black leather jacket he has pasted ACT UP stickers: a bloody hand with the words, "The government has blood on its hands. One AIDS death every half hour." With it is a logo used in New York and more than 50 other cities that have ACT UP branches — a pink triangle and the words "Silence = Death."

O’Malley began his day shortly after 7 a.m. (in time to disrupt breakfast) marching and chanting with thousands of other demonstrators, carrying a homemade sign that said "Koch on AIDS: Don’t Worry, Be Happy." Others carried a New York Newsday front page that quoted Koch saying "I’m Heterosexual."

"And I’m Barbra Streisand," one picketer had added.

"And I’m Gregory Peck," another had written.

Suddenly, O’Malley and a dozen others piled onto Park Row, the street in front of City Hall Park.

"Here we go," said one cop, in riot gear.

Or lock, somebody down the block cried out merrily. "There’s more CD."

For other people their age — most in their 20s and 30s, some teenagers — CD might mean compact disc or, for the professionals, certificate of deposit. For the members of ACT UP, it means civil disobedience. Or, as they say, zaps.

O’Malley has been all over the United States, and in Canada, acting up with ACT UP — zapping in Washington, D.C., five times, getting arrested at the Republican National Convention in New Orleans, protesting the budget in Albany and, earlier this month in Montreal, taking the microphone at the Fifth International AIDS Conference.

But most of his efforts and those of his friends have been in New York. He couldn’t make the Kiss-in on Christopher Street, or the condom-throwing at Helen Gurley Brown (to protest an article on AIDS they considered inaccurate in her Cosmopolitan magazine), or the picket outside the city Department of Housing Preservation and Development, where they blocked the entrance with a rusty armchair and a broken-up toilet to protest the lack of housing for homeless people with AIDS.

But he did picket Northwest Airlines for refusing to fly a man with AIDS back home from China, chanting: "If you get sick in the air, don’t expect Northwest to care."

"I got a phone zap," he says, "tied up their reservation lines."

One by one, the other airlines quickly called up the ACT UP offices and told them they would fly people with AIDS. Northwest revised its policy.

He manned a four-day round-the-clock picket line at Memorial Sloan-Kettering Cancer Center, targeting it as an example of general delays in federal drug testing. Only 844 patients were being treated throughout the country, although money was allocated for 10,000.

In the largest demonstration ACT UP has ever had, the second anniversary spring lie-down against its favorite target, the mayor of New York, ACT UP members coordinate with the help of a cellular phone, the Media Committee hands out slick press packets — with statistic-laden, detailed indictments of city policy — and four camera crews and a dozen photographers train on O’Malley lying in the street.

Two policemen from the 52nd Precinct grab his arms, and a policeman grabs his legs.

With him are the members of three different ACT UP "affinity groups" — the Candelabrums, all dressed in suits; CHER, wearing T-shirts with the face of their namesake, and the Bostocks, sitting in cardboard boxes that are printed with "5,000 homeless."

In the short trip from the street to the paddy wagon, the police start to sing. "Next time I’m going to get a woman," one of the officers says.

“Well, let’s set him down for a minute,” her fellow officer says.

“Yeah, one of the policemen says, who was getting uncomfortable himself. "Was that good for you?"

"Yeah," one of the policemen says.

"It was good for me too."

They all giggle. Then they put him in the police van. Inside, he and his friends start pounding on the wall until it is rocking back and forth, and an officer in the front tells them to knock it off. O’Malley leads the group in his rap song.

"We’re the AIDS Coalition To Unleash Power
We’re working hard nearly every hour
To organize and win a war
Against the AIDS virus and so much more

Outside the van, the street has been cleared of demonstrators but the traffic jam continues, caused now by the press.

"It was a well-coordinated protest," the reporter from WABC was saying to the camera in the middle of the street, next to three other camera crews.

"The cops are saying there were twenty-five hun-
Mike Signorile says later on his telephone at ACT UP media headquarters — his East Village apartment — as he watches for a report on the news at noon. "We've got to up it to three thousand."  

"The story of [the] first five years of AIDS in America," journalist Randy Shilts writes in "And the Band Played On," his account of the AIDS epidemic, "is a drama of national failure, played out against a backdrop of needless death."

The epidemic could have been prevented, Shilts and others have maintained, if the doctors and the scientists and the press — as well as some gay leaders who saw the crisis only as a public relations problem — had responded quickly and responsibly to the first few cases. To an embittered gay community, it seemed that nobody cared about AIDS until 1986, four years into the disease, when movie star Rock Hudson died of it.

But the spread of AIDS is blamed, above all, on the government — local, state and especially federal — for failing to devote the attention, the funds, and the leadership to fight it. Those early complaints were recognized officially last year when James Watkins, chairman of the Presidential Commission on AIDS, called the federal response to the epidemic "inconsistent and not properly coordinated" and this year when the Mayor's Task Force on AIDS concluded that "aggressive leadership and centralized authority has been and remains lacking."

Writer Larry Kramer puts it more bluntly: "It was genocide."

That is why, Randy Shilts writes, "just about anything done to fight AIDS for many years, whether in AIDS education or in lobbying for research, had come solely from the gay community."

The day after the first article that appeared in New York — in The New York Times in July, 1981 — about a rare cancer seen in 41 homosexuals, Kramer and several other prominent gay New Yorkers began the meetings and conversations that within a few months would result in the Gay Men's Health Crisis.

And again, within a month, there was a new organization — with an acronym, a motto ("United in anger and committed to direct action to end the AIDS crisis.") a now-ubiquitous logo: the pink triangle, which the Nazis made homosexuals wear in concentration camps, with the words "Silence = Death."

And they had a new noisy way of getting attention. In their first demonstration, in March of 1987, ACT UP sat down in traffic on Wall Street to protest drug company profiteering in ACT, and hugged the commissioner of the Food and Drug Administration in effigy, to protest the delays in drug testing. The arrest made network news: When the FDA head promised speedier testing and release of new anti-AIDS drugs, Kramer writes in his recent book about AIDS, "Reports from the Holocaust," "Dan Rather gave credit to ACT UP. It was a wonderful beginning."

"Yes we are rude," says Frank Smithson, 34, an early member. "Direct action is rude. That's what Bobby O'Malley, re-enacting the spring lie-down on Gay Street, just around the corner from the site of the Stonewall Rebellion.

GMHC is now the largest and the oldest of a dizzying array of AIDS organizations that raise funds, take care of people, educate, and lobby. There were many organizations, but people were still dying — and that prompted Kramer to write a vituperative play called "The Normal Heart," about the inaction of government and the passivity of gay people in the face of AIDS. None of the existing groups seemed to have the inclination for anger, for politics. None were willing to do whatever was necessary to increase and free up the funding, to stop the discrimination, to lessen the waiting time for new anti-AIDS drugs, to get the government moving.

"Delays are not scientific ones; they're bureaucratic ones."

That is how Kramer saw it two years ago when he was the last-minute substitute guest at a normally tame cultural program at the Lesbian and Gay Community Services Center on West 13th Street. The program, Second Tuesdays, had previously presented speakers like Colleen Dewhurst talking about the theater. Kramer did not want to waste the opportunity.

He made dozens of phone calls: "You better be there," he would say, and hang up.

Kramer gave an impassioned speech about AIDS and about neglect. "Two-thirds of this room could be dead in less than five years," he said. "How long does it take before you get angry and fight back?"

Please see ACT UP on Page 6
Gay Activists: Making a Scene

ACT UP from Page 3

gets attention. With us there screaming at the top of our lungs, and getting on the front pages — that's what these people respond to.

Other gay activists sometimes balk at ACT UP's more outlandish actions, such as when they disrupted several gay functions in which the mayor appeared. "We all carry a lot of anger," says Karen Schwartz of the Gay and Lesbian Alliance Against Defamation. "But when their activism is built entirely on anger, they can lose sight of our ultimate goal.

"If ACT UP sometimes seems unpredictable and rudderless," says Andy Humm of the Coalition for Lesbian and Gay Rights, "that's part of its vitality. This generation of street activists is mainly affiliated with ACT UP."

I've never experienced such intense commitment by so many people in one's lifetime, and it's part of my life," says Darren Rosenblum, 19, from Merrick, L. I., who joined last year after a member of the ACT UP Speaker's Bureau addressed Long Island Gay and Lesbian Youth. A student at the University of Pennsylvania, he is involved in the Philadelphia ACT UP during the school year, and attends meetings and goes to demonstrations with the New York ACT UP during breaks. "Direct action appeals to me. Jews tried to work behind the scenes with FDR during the Holocaust and he didn't do anything."

ACT UP meets every Monday night, at the Center where it was created, to discuss its next zaps, to go over the latest research into drugs, to debate endlessly and take an endless number of votes. Because members elect new leadership every three months — and because they are painstakingly democratic and egaliitarian — the meetings are often charged and chaotic. There are always fewer chairs than people, there is much hugging and shouting, and the agenda snags on administrative issues — whether it would be too bureaucratic to rent an office (they decided to get one but call it a workspace), whether to get a microphone, whether to end the meeting on time. When New York City Health Commissioner Stephen Joseph agreed to meet with an ACT UP contingent of three if they promised not to be disruptive, the ACT UP blackboards were filled with elaborate scenarios vigorously debated — three disruptive, three not disruptive but with a disruptive crowd, three alone but with cameras, etc.

The membership is divided between those people who head committees — tracking drug company and government research, planning actions, raising funds — and those like O'Malley who are part of what Jay Bletcher of the Media Committee calls the "Les Miserables" crowd, people who are there for the color, the demonstrations, the street scene.

Hundreds of both types attend the meetings regularly, not all of them gay, not all of them male. There are some celebrities, like Susan Sarandon, Keith Haring (who has created one of their many distinctive posters) and Martin Sheen. But mostly they are young, hip, white gay men. Post-punk muscular gay white men: severe haircut or ponytail, tiny wire earing, black frame glasses, and T-shirt with one of the many ACT UP slogans. Or downtown button-down: pressed striped Brooks Brothers shirt and jeans just below the knee, wire-rim glasses, and an ACT UP pin. ACT UP has made it fashionable once again to be an activist.

"A lot of people resent that about ACT UP, that they're young, chic, East Village," says Vito Russo, 42, who was at the first meeting and has been involved ever since. "People say 'they're not committed.'"

"Some people may join for social reasons," O'Malley admits. "They don't last long."

O'Malley and many of the others in ACT UP are part. Russo says, of "a whole new generation of young gay people who are sort of New Wave. They really don't have a hangup about being gay. They're more healthy and interested in society."

When he first left Omaha, Robert James O'Malley worked as a waiter and then the manager of a disco in Miami Beach. When he was 21, he had come out to his mother over the telephone. "I didn't mean to tell her. She kept questioning me about this girl I was living with. She kept pressing me and pressing me. I said 'I'm gay and she's just a friend.'"

"She groaned. And then there was dead silence for three minutes. That was the worst part. Then she told me to be careful. I don't think she was all that shocked. She just didn't want to hear it." When his mother visited him after he moved to New York, he inadvertently brought her to a piano bar where most of the customers were gay. "I didn't realize," he started to apologize.

"Oh, I don't care," his mother said. "It's nice here."

Still, he is not close to any of his family, which includes his mother and father, six brothers and two sisters, all back in Nebraska.

In New York, his life quickly became what it is for many young, white, good-looking gay men: going to clubs, hanging out at Uncle Charlie's, a popular gay bar in the Village, and working out at a gym. "I guess I was a disco bunny," he says. "I liked to party, and dance, and just live my life."

He did research about AIDS. When he met Frank Smithson, who was to become one of his roommates, he said, "I've never been very promiscuous. I don't really have that much to say about AIDS."

Smithson had been involved in ACT UP from the first demonstration on Wall Street. He has lost 32 friends to AIDS, and he dissolved his trucking business to volunteer at ACT UP full-time. "We're all living with AIDS," Smithson told O'Malley, using one of ACT UP's slogans.

"Yeah, yeah," O'Malley said. "Every time Frank talked about it, it was a big turn-off."

It was a few months later, at his gym, that O'Malley saw a poster about the AIDS crisis and the government's lack of action. It ended with the words "I'm gay, I'm angry."

Suddenly, O'Malley says, "it hit me. There really was something wrong. The government wasn't responding the way it would to any other emergency. I felt like a real minority."

O'Malley went to the next regular meeting at the Center. Other people have joined ACT UP because they tested positive for the HIV virus, or were diagnosed with AIDS, or because friends were diagnosed, or because friends died.

O'Malley has no personal involvement — at least not as far as he knows. "I really want to take the test," he says. "When I called to get anonymous testing, they kind of discouraged me from doing it. But I was upset about it. They said I was one of the worried well. To a lot of people it's very stressful to know that they're HIV positive. I think I'm well-informed enough so I'd know how to handle it. Early detection is key. There's a lot you can do now."

O'Malley simply went to the one ACT UP meeting, and kept coming back. "I liked the people who were there. Even just by being there. I felt I could contribute something."

"I've seen Bobby change a lot," says Frank Smithson, "from being into himself, working out and going out and living in the sun. He's really come of age, come out to activism. He thinks more about what's going on."

Since that first meeting, O'Malley himself says, "What I value in friends and in a potential boyfriend has changed. My old friends may be the ones turned off now. Oh, ACT UP this, ACT UP that. But to go out and hang out at a bar every night doesn't appeal to me. You can go to a Monday night ACT UP meeting."

Before he joined ACT UP, he had composed no music. He had written two rap songs, the "Fight Back Rap" and "Wrap It Up," about how to prevent AIDS. He indulges in the ACT UP slogans with relish.

If the demonstrations sometimes seem childish, O'Malley says, "the silly chants are all part of the camaraderie... You can't go 24 hours angry. There's a difference."

Still, now even when he visits Provosttown, he puts up ACT UP stickers, almost getting arrested recently for defacement of property.

When he came back from Provincetown to participate in the official 20th-anniversary celebration of the Stonewall riots, he marched with ACT UP, the largest contingent in the parade. He does not know much about Stonewall, and he sees little to celebrate. "After we find a cure," Bobby O'Malley says, "we'll party then."

— journalist Randy Shits

The first five years of AIDS in America is a drama of national failure and needless death. —
A YOUNG NOVELIST

DESCRIBES HOW HE SHED

IGNORANCE AND DENIAL AND

CAME TO JOIN A NEW GENERATION

MOBILIZING ITSELF AROUND

THE ISSUE OF AIDS.

By David Leavitt

IN MAY 1988, I ATTENDED THE AMERICAN BOOKSELLERS
Association convention in Anaheim, Calif. Every A.B.A. has its “big
books,” and that year, one of the biggest was a novel called “At Risk”
by Alice Hoffman. It was the story of an 11-year-old girl who contracts
AIDS from a blood transfusion. I was just one of many gay
men at the A.B.A. that year, and looking back, I think we were all
a little frightened by the brouhaha about “At Risk” —
the huge pyramids of glossy
readers’ copies, the enormous advertising budget, the “six-figure
paperback floor.”

It was not that we doubted the author’s sincerity, or begrudged her the right
to tell whatever story she chose. Rather we sensed, in some deep way, that this
was going to be bad for us. After all, “At Risk” was the story of a child, one of
the so-called innocent victims of AIDS whose stories — because they escape
our society’s prejudices against gay men and drug users — are deemed more
palatable to a “general” audience. What made me nervous was the implica-
tion, inherent in the phrase “innocent victim,” that the majority of people with
AIDS are “guilty” victims, who had brought the disease on themselves by en-
gaging in homosexual sex or shooting drugs. Wasn’t it those people, after all,
who had donated the tainted blood in the first place? Weren’t they on some
level responsible for the plight of the child, the children?

We gay men didn’t talk much about “At Risk” at the A.B.A. Oh, the subject
came up — someone would cautiously ask someone else if he’d read it, then,
even more cautiously, what he’d thought of it. It was all very low-voiced, very
subdued. We were people who made our livings from and devoted our lives to
words; objecting to a novel because of the response it might generate wasn’t a
stance we were used to.

Nearly a year later, The New York Times ran a story about a young, white,
rich, heterosexual woman who said she had contracted AIDS after one night of
sex with a bisexual man. “How Can This Be?” the headline asked. “How Can
Alison Gertz Have AIDS?”

This time, instead of getting nervous, I got angry. It seemed to me at that
moment that all the men and women who had suffered or died from AIDS de-
served to have their names fitted into that sentence, deserved to have their plights announced with that same strong indignation, that horror, that sympathetic vigor. Yet they had not.

I CAN TRACE BACK THE PRESENCE OF AIDS IN MY CONSCIOUSNESS to 1981, when I was 19 and in my second year at Yale. I was standing near the newsstand at the Oakland airport, waiting for the plane that would take me back to school from Christmas vacation, when I noticed a newspaper headline—something about “gay cancer.” For a few seconds, anxiety buzzed around me, like a fly; then I brushed it away and got on the plane. I put the headline out of my mind, but somehow the moment lodged itself in my memory. During the next several years, I was always able to recall it exactly, the way that people of my parents’ generation could remember exactly what they were doing the moment they heard Kennedy had been shot.

Yale University, during the early 1980’s, represented the perfect flowering of the gay rights movement. Being gay was not only socially acceptable, it was trendy. Each spring, the gay and lesbian student groups hosted a week of Gay and Lesbian Awareness Days (known as GLAD) during which both gay and bi sexuals persecuted and murdered by the Third Reich. During GLAD week, there were lectures, workshops, “gay/straight raps,” rallies and dances; and on the last day, hundreds of helium balloons with pink triangles on them were let loose from the lawn in front of Sterling Memorial Library.

The atmosphere was so festive that Larry Kramer, a playwright and novelist who had graduated from Yale in the 1950’s, reported being moved to tears when he came up during 1982’s GLAD week to participate in a panel on the notion of “gay literature” and found himself confronting an auditorium filled to bursting with eager-eyed undergraduates, most of them gay and nearly all of them wearing those notorious pink triangles that would brand them as gay whether they were or not.

Richard Howard, the poet and translator, was on that panel as well, and during the course of the evening made a prediction. This newly-named disease, AIDS, he said, was going to change gay literature utterly, inexorably. From the audience we stared back at him, distant, uncomprehending. Of course we knew about AIDS, but in the protected fishbowl of Yale in 1982, we certainly hadn’t experienced it, and probably didn’t imagine it could have anything to do with us. AIDS, I thought then, was something that happened only to the kind of
As someone who relied on language in trying to come to terms with AIDS, I was appalled by the careless way people spoke about the illness.

view of the many friends of a man with AIDS; its long sentences swirled madly around the never-named disease, just as the characters — dozens of them — swirled around their suffering friend, arguing, constraining, annoying each other, giving each other their anxieties, their metaphors, their links.

“The Way We Live Now” succeeded, for me, primarily because it offered a possibility of catharsis, and at that time, catharsis was something we all badly needed.

particularly in the early days of the epidemic, a diagnosis of AIDS carried with it a crushing burden of guilt; the knowledge that the transmission of the virus could have been avoided if one had slipped when it was too easy. I was of course more than worried — I was terrified, for we had all been told that “worried well” were forever rooting through their sexual histories in an obsessive effort to determine when or if the virus had been transmitted.

What “The Way We Live Now” did so beautifully was to place the small tragedy of each HIV transmission into the larger context of the history of human interaction. In
already badly educated about sex, not to mention AIDS — were put at perhaps the gravest risk of all. (A recent study of nearly 17,000 college students found that two of every 1,000 are now infected with HIV — an appalling statistic, especially given that college students tend to be better educated about sex than their contemporaries who are not in college.) Indeed, just about the only populations that seemed to be gaining any awareness about safe sex were the gay men of New York and San Francisco, and they almost purely through the efforts of organizations like the Gay Men's Health Crisis.

Among gay men things have changed. Though I still know men who believe there is no such thing as "safe sex" — who prefer to lead a celibate life rather than risk infection — they are rare; for the most part, after AIDS as before AIDS, people follow their natures: some have only one sex partner, some multiple sex partners; some seek anonymous sex, some lovers, some both. What's changed is that safe sex has become the norm to which unsafe sex is the frowned-upon exception.

For younger gay men especially, unhampered by memories of the old days, safe sex has become simply what sex is. "Sex positive" is the term I hear used a lot today to describe the newly enthusiastic attitude which has taken hold some eight years into the epidemic — a wonderfully ironic and suggestive term, given that we live in a world in which the word "positive" has a new and distinctly negative connotation.

In the early days of AIDS, many feared that the gay rights movement would be decimated by the epidemic. The gloomy prophets of the early 1980's foresaw a whole generation of men and women retreating into that metaphorical closet, the door of which the gay rights movement had for so long been trying to pry open. AIDS, it was said, would divide the younger from the older; and the generation hardest hit by the disease — the generation that had instigated the famous riot at the Stonewall Inn, a gay bar, 20 years ago, and the gay rights movement that grew out of it — would die out, leaving to as-yet-unawakened future generations the task of starting all over again.

Fortunately, that doomsday scenario has not materialized. On the contrary, a new generation of gay men and women has emerged from the apolitical consumerism (Continued on Page 80)
of the early 1980's and mobilized itself, around the issue of AIDS, into a political force to be reckoned with. Larry Kramer started things rolling with a speech he gave at New York's Gay Community Center several years ago in which he urged his audience to form a grass-roots group that would militate against the Food and Drug Administration to get experimental AIDS drugs approved and made available more quickly.

ACT UP — the AIDS Coalition to Unleash Power — was the organization born of that lecture. Suddenly, those same friends who had conveniently overslept the mornings they were supposed to do volunteer work at G.M.H.C. were filling as many nights as they could with ACT UP events. For unlike G.M.H.C., which had come into being at a time of mourning, and reflected the gay community's sorrow as it struggled to take care of its own ill, ACT UP was, to quote its charter, a coalition of "diverse individuals united in anger and committed to direct action." It was, according to one of its chants, "loud and rude and strong and queer."

The men and women of ACT UP were determined to beat down the notion that the community affected by AIDS was weak, ravaged, deserving only of charity. Instead, they presented an image of a community powered by anger and willing to go to almost any length in order to defend itself. "Health care is a right!" was another ACT UP chant that managed to get across a simple, but essential point: junkies and queers, as much as anyone else, deserved to be taken care of when they got sick.

ACT UP insisted on viewing AIDS as a political as well as a medical issue. Unlike G.M.H.C., the founders of which had lost many friends in quick succession, a good part of ACT UP's membership consisted of very young men and women for whom AIDS represented less a devastating invasion than a presupposed fact of life; some of them had been 14 years old in 1982. To them, AIDS was not a predator which had divided history into a before and after; for them there was no "before." Larry Kramer frequently mentioned the "500 friends" he'd lost to AIDS; in ACT UP there were people who had never known anyone with AIDS until they joined the organization, and who were fighting not for the sake of their friends, but for the sake of strangers.

And they did fight. ACT UP members helped force Northwest Airlines to rescind its policy of refusing passage to people with AIDS by staging a "phone zap," flooding the airline with hundreds of false reservations. They invaded and occupied the offices of Stephen C. Joseph, New York City's Health Commissioner, when he slashed the official estimate of gay men infected with HIV in New York from 250,000 to 50,000. And they stood at the forefront of the effort to get promising drugs tested in non-placebo trials and quickly approved.

ACT UP meets Monday nights in the cafeteria of what used to be a New York public school on West 13th Street. When I arrived the first time, 10 minutes before the meeting's official start, the room was already crammed with almost 300 people — most of them young, and most of them gay, but not all.

There were a lot of people I knew in the crowd, among them Jeff Engel, who, when I'd last seen him two or
three years ago, had been an investment banker on Wall Street. Now, at 29, he was in a one-year pre-medical program at Columbia, planning to pursue a career in community health. He had given up the business suit I'd seen him in for blue jeans and a black T-shirt with ACT UP's famed pink triangle-"SILENCE=DEATH" logo on it. He had given up the co-op in the West Village for a cheap apartment on the Upper West Side. He had been arrested for civil disobedience.

Now, seeing me, he seemed, at the same moment, surprised, skeptical — annoyed that I hadn't come sooner and very pleased that I'd finally gotten there. It was as if we were a late arrival at an inevitable realization everyone else had already come to.

On this night, a man named Raymond, ashien and frail, got up and explained that he was suffering from pulmonary Kaposi's Sarcoma — a rare internal form of the skin cancer which is a common malady among people with AIDS. The only treatment that could help him was Colony Stimulating Factors, an experimental drug manufactured by Schering-Plough, a New Jersey company. Unfortunately, Raymond did not qualify for the company's experimental trials. Repeated requests by both Raymond and his doctors to get him the drug on a "compassionate-use" basis had been turned down by Schering, without explanation.

Everyone applauded as Raymond sat down, and those people who were interested in formulating a "zap" to help him were asked to meet in the shower room. Half an hour later, the spontaneously formed committee emerged with a proposal for a phone zap.

On the appointed day, ACT UP members swamped Schering with phone calls; paralyzing the company's telephone lines. The next week brought the good news that the phone zap had almost completely shut down the Schering switchboard. The company relented, and Raymond got his drug. (When he died two months later, at least he knew that everything possible had been done to try to save him.)

ACT UP HAS SHOWN IT CAN work well in the West Village but, as the impact of AIDS among blacks and Hispanics becomes more pronounced, many members wonder whether the group can "act up" as effectively in Harlem and the South Bronx. And while the organization has ferociously asserted its commitment to the defense of all people with AIDS, its explosive landscape one person's homophobia often clashes with another's racism.

But the problem itself points up how the agenda of gay rights is expanding. In the past, being a gay activist seemed to require a pledged loyalty to a mostly white, all-male "tribe" whose politics of mutual defense took place against a backdrop of relentless consumerism and left little room for a broader view of civil rights. In 1989, by contrast, "the tribe" has given way to a "queer nation" which is assertively coed, multi-racial and anti-consumerist. The closed club has become an open meeting.

What I liked best about ACT UP was its joyousness. Here was a roomful of people who were refusing to accept the common wisdom that as a population affected by AIDS, they were necessarily doomed and hopeless, their lives defined by death. From the shellshocked landscape of the mid-1980's, they had stood up, dusted themselves off and gone to work rebuilding. The ACT UP meetings had a reputation for being a great place to find dates; to me, that meant a great deal — that in New York City, in 1989, it was not a bar, not a disco, but the weekly meeting of an AIDS activist organization that was being talked up as a great place to meet dates.

ACT UP is at its best, of course, when it's acting up. There have been big demonstrations in Washington, where ACT UP staged a symbolic siege of the Food and Drug Administration; in New York, where 3,000 people marched on City Hall to protest the Koch Administration's shameful inadequacy in response to the city's AIDS crisis, and in Montreal, where the group's loud presence at the Fifth International AIDS Conference forced both scientists and pharmaceutical manufacturers for the first time to answer to the people whose lives depend on the drugs they control.

In most cases, acts of civil disobedience are carried out in waves by "affinity groups" formed within the larger organization. The membership of my affinity group, the Candelabras, included three novelists, a nurse, a day-care worker, an East Village bartender and an art history graduate student. At City Hall, according to Larry Kramer's suggestion, we wore business suits, and it was only the next day, when I saw a picture of the Candelabras on Newsday's cover, that I realized how powerful an image that created. Except for the signs and the slogans, we might have been any crew of Wall Street-bound lawyers and bankers and secretaries. Suddenly it was that much more difficult, from both sides, to tell "us" from "them."
The moment, however, which I think will stay with me the longest happened in Columbia, S.C., where I traveled with other members of ACT UP New York, to join in a protest of that state's AIDS policies. (Among other things, the South Carolina Legislature has passed a law mandating the quarantining of HIV-positive people, and making it a felony punishable by up to 10 years in prison for any person to "knowingly expose" another person to the HIV virus.)

In front of the state capitol, the hundred or so ACT UP members marched and chanted and carried signs, as, from atop the massive stone staircase, office workers and members of the Legislature looked on. Several times, the demonstrators staged "kiss-ins," kissing one another as a way of challenging the myth that AIDS can be transmitted through casual contact. Then about 40 demonstrators sat down in the street, blocking traffic, until police officers — most of them wearing rubber gloves — picked them up, bound their wrists with garbage ties, lifted them onto stretchers and took them off in buses to an armory on the edge of town for processing.

Afterward, when everyone was bailed out and we were sitting in a motel room watching the television coverage and listening to the radio, we heard an interview with one of the few native Carolinians who had taken part in the protest. He was wearing a hospital mask, he explained to the interviewer, which he'd taken from the room of the first friend of his who'd died of AIDS, and he'd put a SILENCE=DEATH button on that mask to show that he was protesting on behalf of those friends who had died as well as for himself.

At the end of the interview, the reporter asked him if he wanted to say who he was. He hesitated, explaining that coming out was something one had to do one step at a time; he paused; then he said his name and the town where he lived.

The report ended with those words. I think we'd all expected him not to give his name, to conclude the interview with apology and reluctance; instead, he'd spoken out, branded himself, gone public. Too many people in his life had died brutal deaths for him ever to be silent again.

The radio switched off, we all sat there, humbled, pensive. Then a rustling broke the quiet. "Walter's lost a contact," someone said. Of course — like most of us, he was crying.

That's what I'll always remember best — the way, within a second, we were all on the floor, feeling for that missing lens.
ACT UP ACTIVITIES
For the week of July 10, 1989

TUESDAY, JULY 11

Fundraising Committee, 7:00 p.m.
The Work Space, 111 8th Avenue, Mezzanine Level (SW Corner)

PWA Housing Subcommittee, 7:30 p.m.
347 West 57th Street #3A ("Morrison")

Coordinating Committee Meeting, 8:00 p.m.
The Work Space, 111 8th Avenue, Mezzanine Level (SW Corner)

WEDNESDAY, JULY 12

Outreach Committee + Speakers' Bureau + Newsletter, 7:30 p.m.
ABT Offices, 890 Broadway, 477-3030

Majority Action, 7:30 p.m.
227 Waverly Place #4B @ 7th Avenue, 627-3390

Treatment & Data, 8:00 p.m.
The Work Space, 111 8th Avenue, Mezzanine Level (SW Corner)

THURSDAY, JULY 13

Media Committee, 7:15 p.m.
The Work Space, 111 8th Avenue, Mezzanine Level (SW Corner)

FRIDAY, JULY 14

Actions Committee, 7:30 p.m.
The Work Space, 111 8th Avenue, Mezzanine Level (SW Corner)

MONDAY, JULY 17

ACT UP General Meeting, 7:30 p.m.
The Center, 208 West 13th Street

UPCOMING ACTIVITIES

July 21: Women's Caucus Meeting, 7:00 p.m., DIA Art Foundation, 55 Mercer Street, Contact: 718-857-5557.

CONTACT SHEET UPDATES: Call Tim Smith (h) 212-243-1147 or (w) 952-1700
NOTE: LISTINGS MUST BE RECEIVED BY 10:00 P.M. SUNDAY!!!
# ACT UP CONTACT SHEET

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<tr>
<td>Alan Shaw</td>
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<td><strong>212-787-7313</strong></td>
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<td>* Victor Mendolia</td>
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<td>Jeff Griglak</td>
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<td>Charles Rosenberg</td>
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<td>Robin Crutchfield</td>
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<td>Vincent Gagliostro</td>
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<td><strong>212-768-3806</strong></td>
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<th>P.I.S.D. CAUCUS:</th>
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<tr>
<td>Tim Powers</td>
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<tr>
<td>Brian Damage</td>
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<td><strong>212-246-2879</strong></td>
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<th>TREATMENT &amp; DATA:</th>
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<td>* Richard Elovich</td>
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<td>Ken Wiley F.</td>
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<td>David Z. Kirschenbaum</td>
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<td>Iris Long</td>
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<td>Bob Lederer</td>
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<td>Gene Fedorko</td>
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<td>Mark Harrington</td>
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<td><strong>212-925-5619</strong></td>
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<th>WOMEN’S CAUCUS:</th>
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<td>Rachel Lurie</td>
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<td>Ilith Rosenblum</td>
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<td>Gerri Wellse</td>
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<td><strong>212-533-7673</strong></td>
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<th>LAWYERS:</th>
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<td>David Barr</td>
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<td>Bill Dobbs</td>
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<td>Joan Gibbs</td>
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<td>Jill Harris</td>
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<td>Mike Spiegel</td>
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<td>Mickey Wheatley</td>
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<td><strong>212-995-8969</strong></td>
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<td>Catherine Saalfeld</td>
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<td>Ellen Shapiro</td>
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<td><strong>212-962-6730</strong></td>
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**ACT UP WORK SPACE - 76 NINTH AVENUE - MEZZININE LEVEL 212-989-1114**

* CO-ORDINATING COMMITTEE MEMBER
**ACT UP ACTIVITIES**

*For the week of July 10, 1989*

**TUESDAY, JULY 11**

Fundraising Committee, 7:00 p.m.  
*The Work Space*, 111 8th Avenue, Mezzanine Level (SW Corner)

PWA Housing Subcommittee, 7:30 p.m.  
347 West 57th Street #3A (*Morrison*)

Coordinating Committee Meeting, 8:00 p.m.  
*The Work Space*, 111 8th Avenue, Mezzanine Level (SW Corner)

**WEDNESDAY, JULY 12**

Outreach Committee + Speakers’ Bureau + Newsletter, 7:30 p.m.  
ABT Offices, 890 Broadway, 477-3030

Majority Action, 7:30 p.m.  
227 Waverly Place #4B @ 7th Avenue, 627-3390

Treatment & Data, 8:00 p.m.  
*The Work Space*, 111 8th Avenue, Mezzanine Level (SW Corner)

**THURSDAY, JULY 13**

Media Committee, 7:15 p.m.  
*The Work Space*, 111 8th Avenue, Mezzanine Level (SW Corner)

**FRIDAY, JULY 14**

Actions Committee, 7:30 p.m.  
*The Work Space*, 111 8th Avenue, Mezzanine Level (SW Corner)

**MONDAY, JULY 17**

ACT UP General Meeting, 7:30 p.m.  
The Center, 208 West 13th Street

**UPCOMING ACTIVITIES**

July 21: Women’s Caucus Meeting, 7:00 p.m., DIA Art Foundation, 55 Mercer Street, Contact: 718-857-5557.

*CONTACT SHEET UPDATES: Call Tim Smith (h) 212-243-1147 or (w) 952-1700  
NOTE: LISTINGS MUST BE RECEIVED BY 10:00 P.M. SUNDAY!!!*
### ACT UP CONTACT SHEET

**ADMINISTRATOR:**
- Work Space Group
- Phone Tree Manager
- Mailing List Manager

**TREASURER:**
- Dan Baker

**AT-LARGE REPRESENTATIVES:**
- Tom Keane
- Blane Mosley

**FACILITATORS:**
- Ann Northrop
- David Robinson
- Karl Soehnlein
- Conyers Thompson

**ACTIONS:**
- Jean Elizabeth Glass
- Andy Velez

**CITY ISSUES ADHOC COMM:**
- Joe Ferrari
- Russell Pritchard

**FUND RAISING:**
- Peter Staley

**MAJORITY ACTION:**
- Newsletter Liaison:
  - Dan Williams
  - Blane Mosley
  - Debbie Levine
- IVDU Issues SubC:
  - Jay Blotcher

**MEDIA:**
- Alan Shaw

**MONTREAL AIDS CONFERENCE:**
- Victor Mendolia
- Jeff Griglak
- Charles Rosenberg
- Robin Crutchfield
- Vincent Gagliostro
- Rod Sorge
- G’dali Braverman

**P.I.S.D. CAUCUS:**
- Tim Powers
- Brian Damage

**TREATMENT & DATA:**
- Meeting Facilitator:
  - Richard Elovich
  - Ken Wiley F.
  - David Z. Kirschbaum
  - Iris Long
  - Bob Lederer
  - Gene Fedorko
  - Mark Harrington

**OUTREACH:**
- Speakers Bureau SubC:
- Newsletter SubC:
- PWA Housing SubC:

**P.I.S.D. CAUCUS:**
- Rachel Lurie
- Ilith Rosenblum
- Gerri Wellse

**WOMEN’S CAUCUS:**
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- Ellen Shapiro

**LAWYERS:**
- David Barr
- Bill Dobbs
- Joan Gibbs
- Jill Harris
- Mike Spiegel
- Mickey Wheatley

**DIVA TV:**
- Catherine Saalfield
- Ellen Shapiro

*CO-ORDINATING COMMITTEE MEMBER*
HHC HELD HOSTAGE: The Health and Hospitals Corporation (HHC) runs 11 hospitals in New York City, plus the Emergency Medical Service, and a variety of clinics. While technically it is independent from the city, it has very little freedom. It is funded by city taxpayers, Medicaid and state and federal grants. It is also on the verge of collapse. For example, Bellevue Hospital is overcrowded and understaffed; it is possible to wait for days in the emergency room without being seen. Last year alone it went through four executive directors because of organizational problems. Similar problems exist in every HHC program and facility.

Amazingly, HHC is giving 30 million dollars back to the city this year, despite the fact that it is in desperate need of additional funds. Why? Well, the city is looking for ways to lessen its deficit, and HHC is an easy target. Rather than allow HHC to use this 30 million dollars — which it collected from Medicaid reimbursements — for programs that are in crisis, the city is scooping it up to solve other problems. The city justifies this action by stating that HHC collected more money than its budget stated it needed. This is true but ignores the fact that HHC’s budgets are totally inadequate. If realistic budgets were written and adequate programs created, and this will never happen while the city controls HHC, every penny raised would be essential to HHC’s health.

We cannot allow the city to continue holding our hospital system hostage. Budgets should be designed with the needs of the community in mind, not the balance sheet of non health care related services. T&D is investigating responses to this budgetary maneuvering.

PAYING FOR AIDS DRUGS: Slowly, more drugs are being added to the arsenal against HIV and its related opportunistic diseases (OIs). AZT, aerosol pentamidine (for preventing pneumocystis carinii pneumonia), alpha-interferon (for kaposi’s sarcoma), and DHPG (for cytomegalovirus) have all been approved. All are extremely expensive. However, New York State has a program to help pay for some of these drugs. It’s called ADAP: the AIDS Drug Assistance Program. ADAP will pay drug costs for PWAs/PWArCs who don’t have insurance and do not qualify for Medicaid. For those who have insurance which doesn’t pay 100%, ADAP will make up the difference.

There are limitations. Those whose income is above a certain cap (about 33,000 dollars right now) do not qualify. As of today, it only pays for AZT and PCP prophylaxis, but DHPG has just been approved for the program. Within a few weeks (months?) it will also be covered. Alpha Interferon is being considered.

This program is extremely under utilized. It has lots of extra money. Use it. Tell your friends about it. For more information, call ADAP’s toll-free number: 1-800-542-AIDS. When I called they were very friendly.

DHPG TO BE PAYED FOR BY ADAP: DHPG is a drug just recently approved by the Food and Drug Administration (FDA) to
treat retinitis caused by cytomegalovirus (CMV) infections. Beside the blindness which results from retinitis, CMV can also cause hepatitis, pneumonia, and colitis which results in chronic diarrhea. It is one of the most common OIs that plague PWAs.

It will now be paid for by ADAP. Yea! Spread the news of this major victory.

**FLUCONAZOLE AVAILABLE NOW:** Fluconazole is an antifungal drug used against candidiasis (thrush) and cryptococcal meningitis (an infection of the brain lining and spinal cord). While it is not yet approved by the FDA, it is available for free under compassionate use. However, only those who have already tried to use Amphotericin-B (the approved treatment for cryptococcal meningitis) and found it ineffective can get fluconazole right now. That may soon change; the FDA is currently reviewing a Treatment IND application which, if approved, would make it much more available. This is good news because fluconazole is less toxic than Amphotericin-B and is taken orally. Amphotericin-B is administered intravenously.

If you think you qualify to get Fluconazole under the compassionate use protocol, have your doctor call Pfizer, the manufacturer, at (203) 441-4812.

**MAKING INFORMED CONSENT WORK:** Anyone who enters a drug trial is given an informed consent form which explains the details of the trials, the obligations of the investigators, and what rights the participant has. If the sponsors of the trial guarantee that the drug will be made available to participants after the trial is over, this will also be explained in the informed consent form. Essentially it is a contract between the sponsor and the participants.

Informed consent should protect trial participants. It doesn't always. Forms are sometimes "lost." Certain pages of the form "disappear." The forms may be so illegible that participants don't know what they are signing. Language may be intentionally dense or unclear. Or provisions are simply ignored. Law suits are sometimes necessary to get provisions enforced.

As a result, Congressman Charles Schumer of Brooklyn is considering legislation to strengthen informed consent laws, and T&D will soon be sending him a letter detailing what we think should be done.
Hey, Abe Rosenthal! Let Them Die Off?

“The AIDS epidemic is terrifying enough” without New York Times editorials like this one by Nicholas Wade. The insidious racism, homophobia and misinformation which continue to pervade Times editorials amount to an endorsement of AIDS genocide. How can you consciously represent yourself as one of today’s People Taking Action Against AIDS?

The AIDS epidemic is far from over. But the toll of new cases, which has been rising for years, may at last be about to level off and then decline. Gloomier numbers released this week by the General Accounting Office mask the possibility that the epidemic’s worst rages may be abating.

The G.A.O. study argues that AIDS cases are now under-reported, the true toll being a third higher. Thus total cases by the end of 1991 could reach 300,000 to 480,000, higher than the 285,000 cases projected by the Federal Centers for Disease Control. Representative Henry Waxman, who commissioned the study, cites the new figures to urge more money for AIDS research and health care.

Mr. Waxman draws attention to the new figures in a just cause. But more important for the future shape of the epidemic is the number of new infections. In certain major groups, these seem to be leveling off. If so, the epidemic will peak, and maybe sooner than many forecasters expect. The reason is that the disease is still very largely confined to specific risk groups. Once all susceptible members are infected, the numbers of new victims will decline.

There are already signs of that. The rate of new infections among homosexual men in New York and San Francisco has dropped sharply since 1983, and among white gay men in New York it is now less than 1 percent. Among New York addicts, the proportion infected seems to have stabilized at 50 to 60 percent since 1984. New addicts are still being infected, but in numbers that are offset by those who die of the disease.

Since infection precedes overt disease by five years or so, a decline in infection will be followed five years later by a drop in new cases. Thus cases among gay men in New York should level off soon, though the C.D.C.’s new and wider definition of AIDS may mask any plateau for some months.

The AIDS virus can be heterosexually transmitted to the regular partners of bisexual men and addicts, but is generally not spreading beyond these groups. The evidence comes from interviewing first-time blood donors and people attending sexual disease clinics. In almost all cases, those infected with the virus turn out to be gay, addicted or the sexual partners of those who are.

A disquieting exception to this trend has appeared recently in the South Bronx, where 15 percent of infected people at a sexual disease clinic had no known risk factor. But many had used crack. With the sale of drugs for sex in crack houses, there has been an outbreak of diseases like syphilis, which may foster spread of the AIDS virus through sores that break the skin. Heavy use of crack in a community with many infected drug users could sustain the epidemic among its heterosexuals.

The national caseload of AIDS is the sum of many separate epidemics that started at different times in different cities. If drug abusers in other cities become infected at the same 50 percent rate as in New York, the virus has many new victims awaiting it. But in Los Angeles and Seattle, for instance, the proportion of addicts infected has stayed at about 15 percent. Unless the crack epidemic spreads or some new population becomes susceptible, it’s reasonable to hope that the AIDS plague will at least level off in the next few years.

Advocates for people with AIDS sometimes accept good news badly; steadily rising tolls are such a powerful argument for new resources. When New York City Health Commissioner Stephen Joseph last year halved the estimated number of infected New Yorkers, from 400,000 to 200,000, he met with more rage than relief.

The epidemic is terrifying enough without playing politics with the numbers. The more directly prevention can be targeted at those most at risk—notably black and Hispanic gay men, intravenous drug addicts, crack users and their communities—the sooner the deadly tide will be turned.

We agree with the Village Voice (7/11/89, see reverse), which points out the editorial’s most egregious factual errors and a tone “rejoicing with . . . bloodthirstiness.”
OLD MATH

THE NEW YORK TIMES's Thursday editorial, "Why Make AIDS Worse Than It Is?" which dismissed out of hand the General Accounting Office report on the massive underestimation of AIDS cases, comes at a time when the experts are bemoaning the underfunding of treatment and care for the infected, the sick, and the dying. Yet, incredibly, the Times insisted that the GAO report "mask[s] the possibility that the epidemic's worst rates may be shunting...[and that] the epidemic will peak, and maybe sooner than many forecasters expect."

The Times goes on to insist that the GAO is "playing politics with the numbers," without offering any evidence for the smear.

The editorial is riddled with factual errors. For example: "Since infection precedes overt disease by five years or so, a decline in infection will be followed five years later by a drop in new cases." In fact, the most recent studies show the incubation period between infection and disease is at least 22 years, not five. The information has been published in the paper's own columns. The Times says the rate of new infections among IV drug users in New York City has "stabilized," rejoicing with seeming bloodthirstiness that "new addicts are still being infected, but in numbers that are offset by those who die of the disease." In fact, with everyone from George and Jesse on down bemoaning that IV-drug use and promiscuity are fast rising, this is nonsense, contradicted by studies available to the Times: a recent report by the City Department of Health's Rand Stenebarger suggests major underreporting of AIDS-related deaths among drug users; and a Partnership for the Homeless forecast released in January (about which the Times has yet to print a word) argues that "by 1996 there may be...as many as 50,000 homeless PWAs [People With AIDS] in New York City." The Times supports its murderous optimism by citing the drop in the infection rate among gay men in San Francisco and New York. In fact, what's true for these cities' largely white middle-class, self-aware same-sexers is not the rule between the coasts, where closery, bisexuality, and lack of both AIDS education and confidential testing distort the numbers downward.

More mysteries: doesn't the Times know the Centers for Disease Control estimates found faulty by the GAO exclude people with ARC (AIDS-related complex)? And what about stories the Times began publishing in 1986 on the unreliability of AIDS testing. How do their Pollyannaish projections amount for the "false negatives" who won't be numbered till they fall ill in the next 11 years?

Since the Times has yet to comment on Bush's avoidance of the AIDS crisis, why the timing of this grotesque editorial, only four days after hundreds of thousands of gays marched in the Times's home town demanding more AIDS funding? Here's a clue: the editorial defends Mayor Koch's health commissioner, Stephen Joseph, for halving estimates of the number of infected New Yorkers—thus disculpating the mayor (in an election year) from his failures. If anyone is playing politics with the numbers, it's the Koch-coddling Times.

SILENCE=DEATH

ACT UP's Aids Coalition To Unleash Power is a diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis.

We meet every Monday night at 7:30 at the Center, 208 W. 13th St. Join us!
INVITEES WORKSHOP

"Grassroots, County and State Activists Respond to HIV Infection"

with

Victor Mendolia - ACT UP
Susan Stamler - NY AIDS Coalition
New York Citizens AIDS Lobby
Rich Amato - LI Human Rights Project
Jonathan Silin - Moderator

JOIN US IN DISCUSSING:
- policy and funding issues
- your role in grassroots organizing
- HIV related discrimination
- how to become involved

Thursday, July 13, 1989
7:30 to 9:30 pm

Unitarian Universalist Fellowship
109 Brown's Road
Huntington, NY
two films by ROBERT MAPPLETHORPE

PATTI SMITH/STILL MOVING (1978, 12:42 min.)

and LADY/LISA LYON (1986, 5:00 min.)

and the documentary by SANDY DALEY

ROBERT HAVING HIS NIPPLE PIERCED (1970, 33:00)

at SIMON WATSON, 241 Lafayette Street

Wednesday, July 12th, 7-9 PM

and Thursday, July 13th, 7-9 PM

for more info. call 925-1955

ADMISSION is free to the public with the suggestion that letters are written and addressed to Congress concerning the issues of government funding, censorship and the arts; stamps and stationary will be provided.
EROTOPHOBIA: A FORUM IN SEXUALITY presents

two films by ROBERT MAPPLETHORPE

PATTI SMITH/STILL MOVING (1978, 12:42 min.)

and LADY/LISA LYON (1986, 5:00 min.)

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ADMISSION is free to the public with the suggestion that letters are written and addressed to Congress concerning the issues of government funding, censorship and the arts; stamps and stationary will be provided.
Dear ACT-UP member:

Hi! my name is Gilbert Elbaz and I too am an ACT-UP member. I am also a student at the City University of New York, and I am doing research on -you gessed it- ACT-UP.

What prompted me to do this work was my concern to represent the group accurately. I think that it is essential that the history of ACT-UP be recorded properly by individuals from inside the group. As much as we must be responsible for our health and our community, we must be responsible for the writing of our history.

Yet, being from inside the group does not allow me to write anything I want about it. I know some of you but not all of you, and thus cannot make any assumptions about who you are. Therefore I need your help to fill out this socio-demographic questionnaire. It is pretty detailed for I want my source of information to be as accurate as possible.

THIS QUESTIONNAIRE IS TOTALLY ANONYMOUS. So you can answer the questions in total safety. Of course you do not have to participate, but I cannot emphasize enough the importance of your imput in this study. This is the first time that research is being done on AIDS activists by an AIDS activist himself. Despite much resistance within academia (where the idea of a group studying itself is not a popular one), I managed to get this project accepted. Beyond its academic impact, the questionnaire could be of immediate use by and for the organization. For example, it could help ascertain and even anticipate the decline of involvement of certain members in the organization. Instead of dismissing the issue by simply telling the discouraged members to "take a break", the questionnaire could help in the establishment of support programs and groups more appropriate to the needs of those members.

You do not have to answer all the questions and can withdraw at any time. If you decide to answer the questions, however, do not think that there are "correct" or "wrong" answers. The only answers are the ones that correspond to your personal situation. You are therefore the only one to know them. This is the reason why the questionnaire should be completed individually.

Should you have any comments (and you will) please feel free to insert them in the questionnaire, for there is no such thing as "a perfect questionnaire".

I would like to add that the questionnaire is only one among other methods (such as in-depth interviewing) that will be used to conduct this study. Once the study is completed, the findings will be made available to any respondent requesting them.

Remember, the success of this research will partly depend on the number of returns I will get. I cannot and will not manufacture information about you. So, please help me achieve this arduous and costly task.

If you wish to get in touch with me or wish to be interviewed, my phone number is (212) 237 8694.

see you at the Monday meeting.

Gilbert.
We'd like to know the reasons that brought you to ACT-UP.

We'd like to know the reasons that brought you to ACT-UP.

Please circle the numbers that correspond to your answers. The available responses are:
1 = Extremely Unimportant
2 = Moderately Unimportant
3 = Slightly Unimportant
4 = Doesn't matter one way or the other
5 = Slightly Important
6 = Moderately Important
7 = Extremely Important

1. What was your initial motivation to join ACT-UP?

1. To channel your anger about AIDS into constructive action.......................................................... 1 2 3 4 5 6 7
2. To make some response to the AIDS crisis.......................................................... 1 2 3 4 5 6 7
3. To become more active in the community.......................................................... 1 2 3 4 5 6 7
4. To feel you are supporting a cause you believe in.......................................................... 1 2 3 4 5 6 7
5. To learn to cope with your own problems by helping others.......................................................... 1 2 3 4 5 6 7
6. To do something to protest the mistreatment of PWAs.......................................................... 1 2 3 4 5 6 7
7. To help gay friends do something about AIDS, because others were not doing enough to help persons with AIDS.......................................................... 1 2 3 4 5 5 7
8. To show gay pride.......................................................... 1 2 3 4 5 6 7
9. To offer a skill you have to people in need.......................................................... 1 2 3 4 5 6 7
10. To help members of minority groups.......................................................... 1 2 3 4 5 6 7
11. To learn more about AIDS.......................................................... 1 2 3 4 5 6 7
12. To make new friends.......................................................... 1 2 3 4 5 6 7
13. To learn more about the health care delivery system.......................................................... 1 2 3 4 5 6 7
14. To learn more about drug experiments.......................................................... 1 2 3 4 5 6 7
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<thead>
<tr>
<th>1 = Extremely Unimportant</th>
<th>4 = Doesn't matter one way or the other</th>
<th>2 = Moderately Unimportant</th>
<th>5 = Slightly Important</th>
<th>3 = Slightly Unimportant</th>
<th>6 = Moderately Important</th>
<th>7 = Extremely Important</th>
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<tr>
<td>15. To learn more about the way women are facing the AIDS crisis</td>
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<td>16. To learn more about the way the Black and Hispanic communities are addressing the AIDS crisis</td>
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<td>17. To address in a practical manner your health status</td>
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<td>18. To address in a practical manner the health of your friends</td>
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<td>19. To address in a practical manner the health of your lover</td>
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<td>20. To learn more about politics</td>
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<td>21. To learn more about drug companies</td>
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<td>22. To learn more about the way our economic system works</td>
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<td>23. To work with other oppressed people such as people of color, women and the poor</td>
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<td>24. To learn more about the US government</td>
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<td>25. To learn more about the other major institutions of society such as the Supreme Court</td>
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<td>26. To feel empowered by a knowledge which otherwise you feel would not be given to you</td>
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<td>27. To learn more about scientific research</td>
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<td>28. To learn more about sexuality</td>
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<td>29. To learn more about safe-sex</td>
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<td>30. To meet sexual mates</td>
<td>........................................</td>
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<td>31. To learn more about science</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. To learn more about medicine</td>
<td>........................................</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. To be more responsible with your health</td>
<td>........................................</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
34. To learn more about law................................. 1 2 3 4 5 6 7

35. To understand better how homosexuality
    is perceived in our society.......................... 1 2 3 4 5 6 7

36. To understand better how drug-users are
    perceived in our society............................ 1 2 3 4 5 6 7

37. To fight homophobia.................................. 1 2 3 4 5 6 7

38. To fight for the civil rights of PWA's.............. 1 2 3 4 5 6 7

39. To fight for the civil rights of lesbians and
    gay men.............................................. 1 2 3 4 5 6 7

40. Other (please, specify)__________________________

________________________________________________

________________________________________________
2. In what range does your age fall?

1. less than 18 6. 36-40
2. 18-20 years old 7. 41-45
3. 21-25 8. 46-50
4. 26-30 9. more than 50
5. 31-35


4. What is the job from which you draw the main source of your income? Specify the field in which you work. For example, Health Service, Education, Commerce... Please answer the same questions for your mother, father or those who are or were your legal guardians. If retired, mention the last job title.

<table>
<thead>
<tr>
<th>JOB FIELD</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1. YOURS</td>
</tr>
<tr>
<td>4.2. FATHER'S</td>
</tr>
<tr>
<td>4.3. MOTHER'S</td>
</tr>
</tbody>
</table>

4. If you had the choice, would there be a job that you would rather be doing? 1. yes 2. no

4.5. If yes, which one? (please, specify field)_____________________

4.6. Are you legally married? 1. yes 2. no

4.7. Do you have children? 1. yes 2. no 4.8. if yes, how many?_______

5. In Which of the following groups does the total income of your household fall? (i.e. include the income of the people you live and share the expenses with) Please circle the number that corresponds to your answer.

<table>
<thead>
<tr>
<th>GROUP</th>
<th>1. 0,000-6,000</th>
<th>7. 30,001-35,000</th>
<th>13. 80,001-100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.</td>
<td>6,001-10,000</td>
<td>8. 35,001-40,000</td>
<td>14. 100,001 and up</td>
</tr>
<tr>
<td>3.</td>
<td>10,001-15,000</td>
<td>9. 40,001-45,000</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>15,001-20,000</td>
<td>10. 45,001-50,000</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>20,001-25,000</td>
<td>11. 50,001-60,000</td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>25,001-30,000</td>
<td>12. 60,001-80,000</td>
<td></td>
</tr>
</tbody>
</table>
6. Which of the following best describes your work situation now? (Please, circle ALL that apply)

1. Work full-time for pay
2. Work part-time for pay: number of hours per week
3. Self-employed or free-lance
4. Retired
5. Full-time student
6. Part-time student
7. Unemployed looking for a job
8. Unemployed not looking for a job
9. Never worked

6-1 Does your job offer: (Please circle ALL that apply)

1. Seniority?
2. Tenure?
3. Union support?
4. a non-discriminatory sexual orientation clause?
5. None of the above?
7. Do you define yourself sexually as a:

1. Lesbian?
2. gay?
3. heterosexual?
4. homosexual?
5. bisexual, primarily homosexual/lesbian/gay?
6. bisexual, primarily heterosexual?
7. Other (please specify)?

7-1. How would you describe your sexual thoughts and feelings over the past year? Please, circle one number

Exclusively heterosexual

1 2 3 4 5 6 7

Exclusively homosexual

7-2. How would you describe your sexual actions and behavior over the past year?

Exclusively heterosexual

1 2 3 4 5 6 7

Exclusively homosexual

If you are lesbian, gay or bisexual to what extent:

7-3. were you open about your sexual identity, before joining ACT-UP?

Not at all Out

1 2 3 4 5 6 7

Completely Out

7-4. have you been open about your sexuality since you joined ACT-UP?

Not at all Out

1 2 3 4 5 6 7

Completely Out
7-5. If you are not out completely now, are you out to:

(please, circle the number that corresponds to your answer)

1. Your mother?
2. Your father?
3. Your sister?
4. Your close friends?
5. Your boss?
6. None of the above?

8. What is the highest level of education you have completed?

(please, circle the number that corresponds to your answer).

1. Less than high school degree
2. High school degree or its equivalent
3. Some college or technical school
4. Associate's degree
5. Some graduate work
6. Master's degree (please specify field and school)
7. Doctoral degree (please specify field and school)

9. In what religion were you raised? Please specify the denomination, for example:

Protestant: Baptist, Jewish: reform...

1. Catholic:
2. Hindu:
3. Jewish:
4. Moslem:
5. Protestant:
6. None:
7. Other (please, specify)

9-1 What is your religious preference? (Please, specify)

1. Catholic:
2. Hindu:
3. Jewish:
4. Moslem:
5. Protestant:
6. None:
7. Other (Please specify)
10. What is your "race" or ethnic background, as well as your parents'. After circling the number that corresponds to your answer, please write in your specific ethnic background. For example: Black not of Hispanic origin: Afro-American, Hispanic: Jamaican.

<table>
<thead>
<tr>
<th>Your ethnic background</th>
<th>Your mother's</th>
<th>Your father's</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Black, not of Hispanic origin:</td>
<td>2.</td>
<td>3.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. White, not of Hispanic origin</td>
<td>5.</td>
<td>6.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Other (please, specify)</td>
<td>11.</td>
<td>12.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

11. Approximately, how long have you been a member of ACT-UP?

| 1. 2 weeks or less | 7. 10-12 months |
| 2. 1 month or less | 8. 13-16 months |
| 3. 2-3 months     | 9. 17-20 months |
| 4. 4-5 months     | 10. 21-24 months|
| 5. 6-7 months     | 11. 24-26 months|
| 6. 8-9 months     |               |

11-1. As far as you can remember, could you specify the date you joined ACT-UP?

DAY __________ MONTH __________ YEAR __________
Please, circle the numbers that correspond to your answers.

12. Now we'd like to know about your involvement in ACT-UP.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Many Times</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How regularly do you attend the ACT-UP Monday meeting?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Do you attend other ACT-UP meetings during the week</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. If your answer is positive which one(s):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Are/have you been chair of a committee</td>
<td>1. yes</td>
<td>2. no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. If your answer is yes, which one(s):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PRIOR TO ACT-UP WERE YOU INVOLVED IN OTHER ORGANIZATIONS?

13. Before Joining ACT-UP, did you belong to an organization(s)?
   1. yes     2. no

   2. If yes, which one(s) most impacted on you? Please indicate the name of the organization(s) and whether the organization(s) was gay-identified, political and/or social. Please circle ALL that apply.

   Gay-identified | political | social |
   1              | 2        | 3      |
   1              | 2        | 3      |
   1              | 2        | 3      |

   3. If you belonged to an organization(s) prior to joining ACT-UP, did you leave this organization(s) when you joined ACT-UP?
   1. yes     2. no
4. If yes, why (please, specify) ________________________________________________

5. In the 1988 US presidential election, did you vote? 1. yes 2. no

6. If yes, who did you vote for? ______________________________________________

7. Do you perceive yourself as: (Please, circle the number that corresponds to your answer)
   1. Republican?
   2. Democrat?
   3. Independent?
   4. Socialist?
   5. Communist?
   6. Anarchist?
   7. Other (please, specify)? ________________________________________________

14. Please circle your answer. If your answer is positive, please specify it in the appropriate space.

Before joining ACT-UP, did you:

<table>
<thead>
<tr>
<th>Activity</th>
<th>never</th>
<th>rarely</th>
<th>sometimes</th>
<th>many times</th>
</tr>
</thead>
<tbody>
<tr>
<td>vote in the local elections</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>ever feel strongly about any causes, even if you did not participate in</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>any substantial way?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>contribute money to any other causes?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>lobby for any causes?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>participate in demonstrations</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>participate in civil disobedience</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>deliberately take part in a collective arrest</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
15. Since you joined ACT-UP, did you:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Many Times</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Vote in the local elections</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Read the literature distributed by ACT-UP?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Participate in the workshops, such as the FDA or the women and AIDS teach-ins?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Participate in demonstrations?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Participate in the actions that took place outside New York, such as the FDA action in Washington DC?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Participate in zaps?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Deliberately take part in a collective arrest?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

If yes, which one(s) most impacted on you?
Below is a list of professional groups or bureaucracies which have been said to be directly or indirectly involved in the AIDS crisis. Please circle the numbers that correspond to the extent you think that each of them impacted positively or negatively on the way the national response to the AIDS crisis has been mounted (the Gay organizations have been omitted on purpose).

Please, circle the number that corresponds to your answer.

<table>
<thead>
<tr>
<th></th>
<th>strong negative impact</th>
<th>some negative impact</th>
<th>positive and negative impact</th>
<th>some positive impact</th>
<th>strong positive impact</th>
<th>don't know (dk)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Department of Health</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. US Congress</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Drug Companies</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. The scientific research community</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. The Reagan/Bush administration</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. The Federal government as a whole</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. The administrations of the different states</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. The administrations of the different cities</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. The state bureaucracies in general</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. The major national newspapers, such as The New York Times, New Post or Daily News</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. The major television networks such as CBS, NBC or ABC</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. The diverse religious institutions such as the Church</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Other; (please specify)</td>
<td>1</td>
<td>2 3</td>
<td>4 5</td>
<td>8(dk)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

16-1 In order of priority, which first two do you think have had the greatest impact on the way the national response to AIDS has been mounted. Please, just write in the numbers with a plus or minus sign to indicate whether the impact was positive or negative.

17. In your judgment, should ACT-UP share in joint activities with other groups in order to further those groups' goals? 1. yes 2. no
17-1. If yes, among the following how often should ACT-UP join in political activities with the:

(please, circle the number that corresponds to your answer)

<table>
<thead>
<tr>
<th>Number</th>
<th>Group</th>
<th>Never</th>
<th>Sometimes</th>
<th>Very Often</th>
<th>Don't Know (dk)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Republican Party</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>2</td>
<td>Democratic party</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>3</td>
<td>Liberal party</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>4</td>
<td>Anarchist groups</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>5</td>
<td>Right-to-life groups</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>6</td>
<td>Socialist groups</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>7</td>
<td>Communist groups</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>8</td>
<td>The Rainbow Coalition</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>9</td>
<td>The Homeless Coalition</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>10</td>
<td>Groups against US intervention in Latin America</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>11</td>
<td>Anti-nuclear movement</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>12</td>
<td>Pro-choice organizations</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>13</td>
<td>American Medical Association</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>14</td>
<td>American Society of officials</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>15</td>
<td>Feminist groups</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>16</td>
<td>Green Party</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>17</td>
<td>Peace movement</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>18</td>
<td>Unions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>19</td>
<td>Anti-racist organizations</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>20</td>
<td>ADAPT</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>21</td>
<td>Alcoholic Anonymous</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>22</td>
<td>DAYTOP</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>23</td>
<td>COYOTE</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>8(dk)</td>
</tr>
<tr>
<td>24</td>
<td>Other(s) *(please, specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

17-2. In order of priority, which first two do you think ACT-UP should join in activities with? Please, just write in the numbers that correspond to your answers
17-3. Among the already existing AIDS organizations, which ones do you think ACT-UP should join in activities with, in order to further the goals of those organizations.

**Please circle the numbers that correspond to your answers**

<table>
<thead>
<tr>
<th>never</th>
<th>sometimes</th>
<th>very often</th>
<th>don't know (dk)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The Gay Men's Health Crisis ..................</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. The People With Aids Coalition ...............</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. The National Aids Task Force ................</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. The Minority Aids Task Force .................</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. HEAL ...........................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Body Positive ..................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. ACT-UPS in other cities ........................</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Others (please, specify) ........................</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

17-4. Among the gay organizations that do not specifically focus on the AIDS crisis, which one(s) do you think ACT-UP should join in activities with, in order to further the goals of those organizations?

<table>
<thead>
<tr>
<th>never</th>
<th>sometimes</th>
<th>very often</th>
<th>don't know (dk)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The National Gay Task Force ...............</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. The Lesbian and Gay Community Services Center ........................</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. GLAAD .........................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Dignity ......................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Other (please, specify) ........................</td>
<td></td>
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</tr>
</tbody>
</table>
WE WOULD LIKE TO KNOW IF YOU ARE INVOLVED IN ORGANIZATIONS WHOSE PRIMARY GOALS ARE NOT THE RESOLUTION OF THE AIDS CRISIS. please, circle the number that corresponds to your answer

18. SINCE YOU JOINED ACT-UP, DID YOU:

<table>
<thead>
<tr>
<th></th>
<th>never</th>
<th>rarely</th>
<th>sometimes</th>
<th>many times</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Support the struggle of people who were not engaged in AIDS activism?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. contribute money for causes other than the ones fought for by AIDS activists?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. lobby for causes other than the ones fought for by AIDS activists?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. participate in demonstrations or marches for causes other than the ones fought for by AIDS activists?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. participate in civil disobedience, the primary goal of which was not the end of the AIDS crisis?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. deliberately participate in a collective arrest, the goal of which was not the end of the AIDS crisis?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
PLEASE CIRCLE YOUR ANSWERS. THE AVAILABLE ANSWERS ARE
1=STRONGLY DISAGREE
2=MODERATELY DISAGREE
3=SLIGHTLY DISAGREE
4=NEITHER AGREE NOR DISAGREE
5=SLIGHTLY AGREE
6=MODERATELY AGREE
7=STRONGLY AGREE
8=DON'T KNOW

19.
1. Being openly Lesbian/Gay is a political act. 1 2 3 4 5 6 7 8
2. Lesbian/Gay issues and AIDS issues are closely related. 1 2 3 4 5 6 7 8
3. My involvement in ACT-UP has reaffirmed my Lesbian/Gay identity. 1 2 3 4 5 6 7 8
4. ACT-UP is the organization where I can best express my lesbian/gay identity. 1 2 3 4 5 6 7 8
5. If an injustice was committed to a Lesbian/Gay person, I would always help her/him right away. 1 2 3 4 5 6 7 8

20. We would like to know your feelings about society in general. Please circle your answers.

To what extent do you think that the political institutions, as they currently exist, can meet the needs of:

They cannot meet any of their needs 1 2 3 4 5 6 7

They can meet all their needs

20-1. seropositive people or people with AIDS? 1 2 3 4 5 6 7
20-2. lesbians and gay men? 1 2 3 4 5 6 7
To what extent do you think that the economic institutions (e.g. insurance companies, banks) as they currently exist can meet the needs of:

20-3. seropositive people or people with AIDS

<table>
<thead>
<tr>
<th>They cannot meet any of their needs</th>
<th>They can meet all their needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>

20-4. lesbians and gay men?

| 1 2 3 4 5 6 7 |

PLEASE CIRCLE YOUR ANSWER

20-5. Over the last eight years have you personally experienced:

a. any anti-gay insult?

| 1 2 3 |

b. any anti-gay act of violence?

| 1 2 3 |

20-6. Over the last eight years have you witnessed:

1. any anti-gay insult?

| 1 2 3 |

2. any anti-gay act of violence

| 1 2 3 |

20-7. How satisfactory is your relationship with your:

<table>
<thead>
<tr>
<th>Totally Unsatisfactory</th>
<th>totally Satisfactory</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>

1. family?................................. 1 2 3 4 5 6 7
2. friends?............................... 1 2 3 4 5 6 7
3. coworkers?............................. 1 2 3 4 5 6 7
4. partner/lover?....................... 1 2 3 4 5 6 7
5. husband/wife?....................... 1 2 3 4 5 6 7
6. Boyfriend/girlfriend?............... 1 2 3 4 5 6 7

20-8. How satisfactory is your life:

<table>
<thead>
<tr>
<th>Totally Unsatisfactory</th>
<th>totally Satisfactory</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>

1. intellectually?...................... 1 2 3 4 5 6 7
2. romantically?....................... 1 2 3 4 5 6 7
3. sexually?............................ 1 2 3 4 5 6 7
4. professionally?..................... 1 2 3 4 5 6 7
Now we’d like to know about your views on the testing issue and your health status. We remind you that your responses will remain totally anonymous.

21. Have you been tested for HIV antibodies
   1. yes 2. no

   21-1. if no, why not (please specify)

   21-2. Are you seropositive?
   1. yes 2. no
   If no, please go to question 22

   21-3 If yes, please circle the answer that best characterizes your health status
   1. HIV asymptomatic
   2. ARC
   3. AIDS
   4. Other (please specify)

   21-4. If you are seropositive, did you know it before joining ACT-UP?
   1. yes 2. no

   21-5 If you are seropositive, to what extent did you disclose your health status to:

<table>
<thead>
<tr>
<th>Not disclosed at all</th>
<th>1 2 3 4 5 6 7</th>
<th>Totally Disclosed</th>
<th>1 2 3 4 5 6 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>family?</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>siblings?</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>friends?</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>coworkers?</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ACT-UP members?</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

   22 Did you lose a person(s) dear to you to AIDS?
   1. yes 2. no

   22-1 if yes, how many
PLEASE CIRCLE YOUR ANSWER. THE AVAILABLE ANSWERS ARE:
1=STRONGLY DISAGREE  4=SLIGHTLY AGREE
2=M0DERATELY DISAGREE  5=M0DERATELY AGREE
3=SLIGHTLY DISAGREE  6=STR0NGLY AGREE
8=D0NT'KN0W

23. AS A MEMBER OF ACT-UP:

1. I understand better the legal system of this country ........................................ 1 2 3 4 5 6 8(dk)

2. I understand better the way scientific research is conducted........................................ 1 2 3 4 5 6 8(dk)

3. I understand how to practice safer sex........................................ 1 2 3 4 5 6 8(dk)

4. I have learned to educate other people about AIDS........................................ 1 2 3 4 5 6 8(dk)

5. I understand better my sexuality........................................ 1 2 3 4 5 6 8(dk)

6. I am sometimes disappointed because the focus is not always on AIDS ........................................ 1 2 3 4 5 6 8(dk)

7. I have a better understanding of the way the media function........................................ 1 2 3 4 5 6 8(dk)

8. I feel proud to be gay........................................ 1 2 3 4 5 6 8(dk)

9. I have learned about holistic medicine........................................ 1 2 3 4 5 6 8(dk)

10. I have come to realize that being open about one's seropositive status is a political act........................................ 1 2 3 4 5 6 8(dk)

11. I see the need to increase our efforts to outreach to other communities........................................ 1 2 3 4 5 6 8(dk)

12. I understand better the power structure of the United States........................................ 1 2 3 4 5 6 8(dk)
1. I understand better how other minorities are oppressed.......................... 1 2 3 4 5 6 8(dk)
2. I realize how women are oppressed.......................................................... 1 2 3 4 5 6 8(dk)
3. I think that issues of class should be more addressed during the meetings.......................... 1 2 3 4 5 6 8(dk)
4. I have a good handle on the way the drug protocols are conducted.......................... 1 2 3 4 5 6 8(dk)
5. I see the connection of the AIDS crisis to other social problems............................................. 1 2 3 4 5 6 8(dk)
6. I realize that the group is too radical.......................................................... 1 2 3 4 5 6 8(dk)
7. I have made a lot of friends.......................................................... 1 2 3 4 5 6 8(dk)
8. I feel intimidated to speak in public.......................................................... 1 2 3 4 5 6 8(dk)
9. I have learned to take control over my body.................................................. 1 2 3 4 5 6 8(dk)
10. I have become more critical of science.................................................. 1 2 3 4 5 6 8(dk)
11. I think that we often lose sight of our focus during the meetings.......................... 1 2 3 4 5 6 8(dk)
12. I realize that I still find myself pretty much isolated.................................................. 1 2 3 4 5 6 8(dk)
13. I have learned to understand better how lesbians and gay men are oppressed.......................... 1 2 3 4 5 6 8(dk)
14. I am convinced that we should address more frequently the international aspects of the epidemic.......................... 1 2 3 4 5 6 8(dk)
15. I have become more critical of the scientific community.................................................. 1 2 3 4 5 6 8(dk)
16. I understand better the position of religious institutions such as the church with regard to the gay community.......................... 1 2 3 4 5 6 8(dk)
17. I understand better the political differences within the gay population.......................... 1 2 3 4 5 6 8(dk)
1=Strongly Disagree
2=Moderately Disagree
3=Slightly Disagree
4=Slightly Agree
5=Moderately Agree
6=Strongly Agree
8=Don't Know

30. I keep myself informed of the drug trials currently underway... 1 2 3 4 5 6 8(dk)
31. I admit that it is hard to be admitted in certain circles of friends that are already established in the organization... 1 2 3 4 5 6 8(dk)
32. I am sometimes disappointed because the discussion are too technical and difficult to understand... 1 2 3 4 5 6 8(dk)
33. I often feel uncomfortable because there are no support groups when I am "burned out"... 1 2 3 4 5 6 8(dk)
34. I am sometimes discouraged because the group is not radical enough... 1 2 3 4 5 6 8(dk)
35. I am convinced that the group should spend more time on minority issues... 1 2 3 4 5 6 8(dk)
36. I have learned to fight homophobia... 1 2 3 4 5 6 8(dk)
37. I have learned to fight for the rights of seropositive individuals... 1 2 3 4 5 6 8(dk)
38. I wish there were more social events planned by the group... 1 2 3 4 5 6 8(dk)
39. I am convinced that the group should spend more time addressing women's issues... 1 2 3 4 5 6 8(dk)
40. I am convinced that sexuality should be discussed publicly... 1 2 3 4 5 6 8(dk)
41. I realize that I learned a great deal about lesbian and gay history... 1 2 3 4 5 6 8(dk)

23-1. Is there anything in ACT-UP that you don't like? 1. yes 2. no

1. If yes, please explain briefly what you most dislike about the organization.

2. Would you say that what you don't like about ACT-UP caused you to be significantly less involved in the organization? 1. yes 2. no

23-2. Did ACT-UP change your life in any dramatic way? 1. yes 2. no
1. If yes, please explain briefly how

WHAT IF TOMORROW THERE WAS A CURE FOR ALL THE SEROPOSITIVE INDIVIDUALS REGARDLESS OF THE DEGREE TO WHICH THEY ARE AFFECTED BY THE DISEASE ??

24. According to you, would there still be a reason for ACT-UP to exist?  1. yes  2. no

24-1. If yes, please briefly explain why?

THANK YOU FOR SPENDING THE TIME...

YOU MAY MAIL OUT THE QUESTIONNAIRE TO:

GILBERT ELBAZ
5 WEST 63RD STREET  #1238
NEW YORK, NY  10023

OR RETURN IT NEXT MONDAY (7-3-89) AT THE CENTER.  THANK YOU.

GILBERT
JOHN S. JAMES’ REPLY FORM

☐ YES! I want to take positive action to help the men and women activists of
ACT UP bring new AIDS drugs and treatments faster to the people who need
them. Here’s my gift of:

☐ $500  ☐ $250  ☐ $100  ☐ $50**
☐ $35*  ☐ $25  ☐ $75  ☐ $

☐ **I’ve enclosed $50 or more,
please send me a limited
edition of the
4-color
Keith Haring
ACT UP poster.

☐ I’m interested in ACT UP T-shirts,
posters, stickers and publications.
Please send me an order form.

☐ *I’ve enclosed at least $35. Please
send me ACT UP’s National AIDS
Treatment Research Agenda.

Please return this form with your gift in the reply envelope enclosed or mail to: ACT UP Box 261, 70A Greenwich Street, New
York, New York, 10011. Because ACT UP is an activist organization, contributions to it are not tax-deductible. All of your fellow
ACT UP supporters thank you for your moral and financial support.
FACTS ABOUT ACT UP

ACT UP has no paid employees, no executive director, no president, and no chairperson. No pointless overhead and no bureaucratic fat.

Instead, ACT UP is comprised of a series of affinity groups, ad hoc and standing committees, and one overall coordinating committee.

Every single Monday night (for more than two years) between 250 and 600 ACT UP members meet in a cramped—and this last summer, often hot and sweaty—room on the ground floor of the Gay and Lesbian Community Services Center in Greenwich Village in New York.

Each meeting is run by Robert's Rules of Order with a revolving team in charge of conducting the meeting. Direct actions, expenditures, and other activities are approved—or disapproved—at the weekly meetings.

In its commitment to direct action, ACT UP is unique among AIDS organizations. Right in ACT UP's statement of purpose, the commitment to direct action is explicit and uncompromising:

"ACT UP is a diverse non-partisan group united in anger and committed to direct action to end the AIDS crisis."

It's democracy at its best. And it works.
KEITH A. HARING
ACT UP
BOX 261
70-A GREENWICH AVE.
NEW YORK, NEW YORK 10011
Sometimes when we set things aside we forget them.

ACT UP New York's urgent and immediate need for funds is too critical -- and the progress at the FDA and NIH too important -- to set aside this appeal aside and forget to respond.

I hope you will respond generously and quickly. Thank you.

Yours in direct action,

Keith A. Haring

P.S. My worst fear about this direct mail fundraising project is that people might think this is just a direct mail letter signed by a "celebrity" who is simply endorsing a group, but isn't really involved. That is not the case. I go to ACT UP weekly meetings, I go to demonstrations, I've given money and art repeatedly and I truly believe every word I've written here. It is so important that everybody do what they can... Thanks.

Here are the other AIDS activist groups:

ACT UP Boston
P.O. Box 483
Kendall Square Station
Cambridge, MA 02142
(617) 492-2887

ACT UP Rhode Island
P.O. Box 3156
Providence, RI 02906
(401) 461-4191

ACT UP Albany
727 Madison Ave.
Albany, NY 12208

ACT UP Syracuse
P.O. Box 690
Syracuse, NY 13201
(315) 475-1544

ACT UP Philadelphia
P.O. Box 15919
Philadelphia, PA 19103

Cry Out!
P.O. Box 71096
Pittsburgh, PA 15213
(412) 683-9741

Out! DC
P.O. Box 18781
Washington, DC 20036
(301) 794-8829

ACT UP Atlanta
P.O. Box 57089
Atlanta, GA 30303
(404) 286-6247

ACT UP Kansas City
P.O. Box 10085
Kansas City, MO 64111
(816) 753-5930

ACT UP New Orleans
P.O. Box 20501
New Orleans, LA 70172

G.U.T.S.
P.O. Box 190712
Dallas, TX 75219
(214) 471-5771

ACT UP Austin
1118 W. 6th St., Suite C-103
Austin, TX 78703
(512) 322-9270

ACT UP Denver
432 S. Broadway, #100
Denver, CO 80209
(303) 830-0730

ACT UP Minnesota
P.O. Box 50201
Minneapolis, MN 55405
(612) 377-7007

ACT UP Long Beach
5595 E. 7th St., #174
Long Beach, CA 90804
(213) 435-4346

ACT UP Chicago
3225 N. Sheffield
Chicago, IL 60657
(312) 509-6802

ACT UP San Francisco
2300 Market St., #68
San Francisco, CA 94114
(415) 563-0724

Fight For Life Committee
6231 Southwest 10th Ct.
N. Lauderdale, FL 33068
(305) 972-0393

Gay-Leather March Activists
P.O. Box 19530
Cincinnati, OH 45219
(513) 281-7496

ACT UP Chicago
3225 N. Sheffield
Chicago, IL 60657
(312) 509-6802

ACT UP San Francisco
2300 Market St., #68
San Francisco, CA 94114
(415) 563-0724

ACT UP L.A.
P.O. Box 26601
Los Angeles, CA 90026
(213) 668-2357

ACT UP Portland
P.O. Box 6352
Portland, OR 97228
(503) 288-7853

ACT UP Seattle
1206 E. Pike, Suite 814
Seattle, WA 98122
(206) 322-2873
before has so much of such a comprehensive overhaul of federal policy been implemented in so little time.

Since the beginning of 1989, ACT UP has published in excess of 200,000 pages each month of policy statements, research analysis, treatment, drug and political information. That's amazing.

By consensus decision, nothing ACT UP New York publishes is copyrighted. In fact, everything ACT UP publishes is aggressively distributed around the nation, and much of it around the globe, where it fuels the fires of activism, of self-empowerment and social change.

I hope you can take a few moments to consider how critical ACT UP's positive life-promoting actions have been... for all of us.

As a person with AIDS, as a gay man and as a human being concerned with the future of our planet, I am horrified at the thought of where we would be in this health crisis without ACT UP.

*** ACT UP needs and deserves your moral and financial support.

*** By giving to ACT UP you don't have to endorse every -- or any -- demonstration and action.

*** All you have to do is recognize ACT UP's importance and understand how vital their progress is for those who are fighting to LIVE.

ACT UP's work has dramatically expanded these past few months, mostly because of the breakthroughs with the FDA and NIH. ACT UP has no cash reserves and operates on a day-to-day hand-to-mouth existence.

As vast as ACT UP New York's popular support and volunteer resources are, they still must raise thousands of dollars to pay for the costs of producing and distributing so much printed material as well as organizing demonstrations and meetings with government officials.

Please, I urge you to go get your checkbook right this minute and write out the most generous life-promoting and life-saving check you can afford.

We need your help and would be proud to have you join us.

Also, if you're ever able to join a Monday night ACT UP New York meeting, I'll probably see you there. In any case, there may be another AIDS activist group in your immediate area.

Since ACT UP New York's birth in March of 1987, dozens of other grassroots AIDS activist groups have sprung up across the nation. Many have proudly adopted the ACT UP name. At the end of this letter I've included a list of these groups. I strongly urge you to give them a call, volunteer and support their efforts financially, also.

(Other side, please)
ITEM: When powerful Forbes magazine last summer presented the bizarre theories of an oddball AIDS commentator as fact, ACT UP immediately organized a demonstration outside Forbes Manhattan office.

The result?

Malcolm Forbes, the magazine's publisher, invited the demonstrators inside to his office to hear their views. He agreed to publish a retraction. And to publish both an apology and ACT UP's "Fact Sheet" distributed at the demonstration. And endorse it. And he did.

I'm not going to misrepresent how ACT UP achieves its mission. A lot of the above successes -- and many others -- were a direct result of ACT UP's demonstrations and civil disobedience.

Those demonstrations are always loud and noisy, sometimes they're rude, and they are guaranteed to make someone angry. And sometimes people get arrested.

Personally, I think it's appalling that American citizens must go to the streets and get arrested to get their government to do what it ought to do anyway.

But the bottom line is: ACT UP's demonstrations work. I believe they work for two reasons.

First because of the raw pressure.

ACT UP pinpoints its pressure at critical times. Demonstrations combined with sophisticated use of the media results in dramatic impact on targeted policy-makers and institutions. Those who delay or thwart ACT UP's demands are quickly motivated to re-evaluate their role.

The second reason the demonstrations work is because ACT UP does its homework. Its activists focus on what is truly achievable, rather than simply opportunities to vent steam.

ACT UP's policy statements are expertly written, with input from medical professionals, and grounded in sophisticated policy analysis. Frequently, through effective infiltration, ACT UP has the assistance of "moles" inside the institutions we're seeking to change.

One of ACT UP's most historic documents, presented at the International AIDS Conference in Montreal, is the National AIDS Treatment Research Agenda, which has already become a blueprint for action around the globe.

National Institutes of Health and FDA officials have labeled the National AIDS Treatment Research Agenda an "extraordinary" document.

Never before had such a comprehensive plan been written for overhauling the nation's system of drug and treatment approvals. And never
I believe you are such a person, and that's why I'm writing you.

What most people know about ACT UP is what they have learned from the mass media. But until recently, the press only covered ACT UP's loudest demonstrations and represented ACT UP as a rude "doom and gloom" group focused on death and dying.

But the reality is different.

ACT UP New York is a powerful and phenomenally effective advocacy group full of life and joy and vitality and excitement. It's also a lot of fun, which is evident at any of the weekly Monday night meetings. I know that first hand.

Many ACT UP members and supporters, including me, find our involvement enormously satisfying because we can see the tangible results of our efforts... almost on a weekly basis.

In just the past few hot summer months, the people of ACT UP made history in several ways.

ITEM: For the first time in history, a drug company (Bristol-Myers) in conjunction with an activist organization (ACT UP) and the FDA have worked together to release a drug for treatment earlier in the approval process than ever before.

The result?

The head-to-head testing of AZT vs. DDI isn't yet complete. But with DDI's release, thousands of people with AIDS (PWAs) who cannot tolerate AZT's toxicity now have an immediately available alternative choice. A choice so important, and an approval step so unusual for the FDA, that it was a major news story.

ITEM: When ACT UP introduced the concept of parallel track testing last June -- based on the formula that expedited the release of DDI -- few thought the idea would progress rapidly. But it has. A few weeks ago, the FDA announced an Advisory Committee to nail down the details establishing parallel track testing for a wide range of drugs. An Advisory Committee which includes an ACT UP member.

That's historic.

ITEM: For the first time since 1961, the FDA last June gave marketing approval to a sight-saving drug (DHPG) based on overwhelming evidence of its efficacy but without formal clinical trials... because of ACT UP's uncompromising pressure.

The result? Thousands of PWAs can still see and avoid the blinding of cytomegalovirus-related retinitis, a leading AIDS-related infection.

(Other side, please)
--- It isn't for those who are afraid of ethnic, religious, sexual and political diversity.

--- ACT UP isn't for people who are so deep in denial they refuse to talk about AIDS and avoid those who do.

--- And ACT UP certainly isn't for the "good gays" and others who believe that the government will find treatments and a cure in due course and nothing we do can make it happen faster, so "why make trouble?"

So if it's not for all those people, who is ACT UP for?

ACT UP is for men and women who are willing to accept responsibility for their own power to change the course of the epidemic.

These men and women of ACT UP New York I'm asking you to join have truly become the conscience of our community and the primary catalyst for AIDS-related policy change.

A year ago I was reading Frances Fitzgerald's Cities on a Hill about how the gay community in San Francisco has changed. In the first chapter, Fitzgerald writes about a man who finds a Kaposi's Sarcoma lesion on his body for the first time.

As I was reading that passage, my eye was drawn to what, until then, I had thought was a bruise on my arm. For the first time the thought crossed my mind that it might be KS.

In the year since I've been relatively healthy and working more productively than ever. But as I had to become more familiar with treatment options and various drugs "in the pipeline," my frustration grew dramatically.

I became increasingly committed to the importance of direct action -- through ACT UP New York -- to bring new drugs and treatments to more people who need them faster.

Not just because I'm now ill, but because the FDA and NIH's present systems are fundamentally flawed, and I didn't fully understand that until my own life became dependent on those systems.

Quite frankly, the progress ACT UP makes today will most benefit persons who probably don't even yet realize they are HIV positive.

Since the beginning of the epidemic (if not the beginning of time), the medical and political bureaucracies have moved with urgency only in response to intense pressure.

Anger can be a powerful fuel. ACT UP is for people who want to transform their anger into constructive action and intense pressure that will save lives.
Dear Friend,

Are you positive?

For a long time that was the question which I and many of my friends feared most.

By "positive" we meant HIV positive.

I learned the answer to the question of my own positivity last year when I found a purple spot (Kaposi's Sarcoma) on my arm.

But when I ask you, "Are you positive?," I'm not talking about HIV.

I'm referring to an attitude of pride and power that can beat the AIDS epidemic. The positive attitude I'm asking you about is as vital as better drugs in the fight against AIDS.

I've found that positivity through my personal involvement with a one-of-a-kind organization: ACT UP New York, the AIDS COALITION TO UNLEASH POWER.

"Positive" means terror to many people at risk for AIDS. But at ACT UP, "positive" also has a different meaning: to take positive life-promoting steps to fight AIDS... to make a difference, positively.

Almost anything you do about AIDS is positive. Like when you're spoon-feeding your best friend who's hospitalized with AIDS-related blindness. It keeps your friend from starving, and that's positive.

Or when you're writing letters or calling politicians who don't give a damn about whether you live or die. Pressure is what makes them listen and act, and that's positive.

So many of us have taken positive steps like these thousands of times over the past few years.

But I'm writing to ask you to take one more, by helping ACT UP New York to continue its extraordinary successes of the past few months through the upcoming winter.

But before you read another word, I want to warn you:

ACT UP is not for everyone.

--- It isn't for those who are afraid of making noise, raising hell and throwing around words like "civil disobedience," "arrest," and "jail."

(Other side, please)
How to Negotiate with Drug Companies

8.23.89

T+D

1. Know your shit. Knowledge is power. Every significant gain won by ACT UP has flowed from our unassailable command of the issues. There is a wealth of information about new AIDS treatments. The fact that T+D does not meet at ATR headquarters, and does not have a central drug archive, is a significant impediment to democratizing drug knowledge within T+D and within ACT UP. Hopefully, the new materials developed for the September teach-ins will help "bridge the info gap."

In the interim, we should develop a central T+D archive at the ACT UP workspace, which should include:

* The Stockholm and Montreal Abstracts
* The latest edition of the AIDS Treatment Registry
* A complete set of John James' AIDS Treatment News
* The T+D Glossary, AIDS Drugs Now (testimony to the Lasagna Committee), National AIDS Treatment Research Agenda, and Parallel Track documents
* Copies of discussions with Fauci, Cooper & Bristol-Myers over ddI and Parallel Track (the correspondence and conversations provide a useful template for drug negotiations)
* Copies of GMHC's Treatment Issues, especially its compilation issue
* The FDA guidelines and conference handbook distributed at the CRI conference in July, 1989
* A complete set of the AmFAR AIDS/Experimental Treatment Directory issues (sometimes drugs are listed, then dropped. Old issues include interesting essays and drug company contacts, sometimes out of date, but still useful).

People working on drug negotiations should maintain files about each priority drug, and should be able to xerox materials from the above to use in their work.

ACT UP's responsibility to the AIDS community includes being honest about new drugs. Sometimes, not much is known. We must always emphasize the bad side effects along with the promise of new treatments. Otherwise, if the drug becomes widely available, people with HIV may injure themselves by taking the new drug based on hype.

2. Call and Write the Sponsor and FDA. The start of negotiations is figuring out who you're dealing with. Call the drug company contact listed in AmFAR and find out who is in charge of developing this particular drug. Call the FDA and request the C.S.O. (consumer safety officer) for the drug. Ask both contacts for the latest information about the drug, trials underway, access outside of trials (compassionate use, etc.). Don't take "no comment" for an answer. You have a right to know! ACT UP is watching.
Then, write the sponsor a letter describing ACT UP's dissatisfaction with the slow pace of research and restrictions on access. Carbon copy the letter to the FDA (to Frank Young, Ellen Cooper, people in consumer affairs and the CSO). Ask for a meeting.

3. **The Meeting.** Before ACT UP designs an action, it is fairest to have a meeting with the recalcitrant drug company. Sponsors are usually shocked to find out how much we know and how much contact we have with the Federal drug establishment. Often, it seems we have more contact than they do. Emphasize that ACT UP can help them get their drug out faster (if it's a good drug). Then make veiled allusions to bringing 3,000 angry AIDS activists to their headquarters and staging a media extravaganza. Refer to the burgeoning AIDS drug underground if they act like they have a monopoly on the drug. If they're abusing the Orphan Drug Act, tell them so.

4. **Follow-Up.** Usually, it's a good idea to follow up on the first meeting with a letter. If the outcome was good, tell them so. If it was unsatisfactory, say so and either request a further meeting or allude to other action we might take. With Bristol-Myers, they weren't prepared for the first meeting and were much more conciliatory the second time around.

Follow-up also includes a complete report to T+D and, when necessary, to the Floor. Steven Gendin should be told about the results so he can report them in the T+D Digest. There should probably be a system for written reports which would be kept in the central drug file.

5. **The Action.** Most rewarding of all is the well-orchestrated drug company action. For the most part, pharmaceuticals are much more worried about their public image than monolithic government bureaucracies. Make sure the action plan is well designed and that you have what you need for a successful action. Sometimes this includes handcuffs or electric power drills.

Crucial to the success of a drug company action is media coverage. Peter Staley made sure all 3 Japanese networks covered the Kowa Zap in July, 1988. The company released dextran sulfate to Americans the very next week. A good fact sheet and cogent demands are also crucial.

6. **The Impact.** Increasingly, ACT UP/New York is working with other AIDS groups around the country. Some sponsors are closer to other ACT UPs. The Astra zap was coordinated by ACT UP/Boston with New York representation. We should work closely with other ACT UPs and AIDS groups around the country for maximum impact.

7. **Distribution.** Just because a drug becomes available on Compassionate Use, Treatment IND or Parallel Track will not guarantee that people who need it get it. We need to form a Task Force to ensure access to new drugs to people who get their health care in HHC hospitals and public health clinics. We should work with New York City and state health officials to guarantee equity of access without regard to ability to pay.
FREE AZT! FREE PENTAMIDINE! FREE BACTRIM! FREE DHPG! FREE ALPHA-INTERFERON! FREE LEUCOVORIN! And only 200 people in the entire state of New York have taken advantage of the ADAP program which makes these drugs available. (ADAP is an acronym for AIDS Drug Assistance Program.) To qualify for the program, one must:

1) Have a doctor to fill out the 3-page form.
2) Have an annual income less than $44,000.
3) Be ineligible for Medicaid assistance.
4) and have...
   - for AZT, a T-4 count below 400 (or have had one).
   - for Bactrim, Pentamidine or Leucovorin, a T-4 count below 200 (or total T-4 count representing less than 20% of circulating lymphocytes) or have had an episode of PCP.
   - for DHPG, diagnosis of CMV infection.
   - for alpha-interferon, a KS diagnosis.

ADAP’s fiscal year ends in October, and right now the program is running an $8 million surplus!!! If we want this funding to continue, it is imperative that we make use of the program. So please... tell everyone and anyone you think might qualify and benefit from the program. (If you are already covered through a health insurance plan but meet the other ADAP requirements, ADAP will reimburse you for any deductible or co-payment you paid out of pocket for these drugs.

GM-CSF UPDATE: As reported in last week’s Digest, T&D has begun negotiations with Dr. William Darrow (Senior Vice President for Medical Operations) at Schering-Plough to request accessibility to GM-CSF (Granulocyte-Macrophage Colony Stimulating Factor). Schering’s GM-CSF is already in Phase III trials! That means it has already been tested for toxicity and efficacy and is now only being monitored to confirm earlier findings of efficacy and to detect potential long-term toxicity. And still they refuse us access to it.

Dr. Darrow told Larry Kramer that he wants to wait and see how Bristol Myers’ parallel track approach to ddl works before he will be willing to seriously discuss the possibility of making GM-CSF available. Darrow maintains that Schering’s record on making GM-CSF available under Compassionate Use is beyond reproach. We know differently. Even if his claim (that Schering has made GM-CSF available to nearly 100 PWAs) were true, that number falls well short of the total population in need of this white-blood-cell-boosting drug. Unless Schering changes its tune soon, we’ll be in their lobby quicker than they can say “Granulocyte-Macrophage Colony Stimulating Factor.”

WOMEN’S TREATMENT & DATA: Once again, T&D is making a plea for representation by women and people of color. Our meeting with MAC (Majority Actions Committee) several weeks ago brought a number of...
important issues to the fore, and we are planning a joint meeting with the Women's Caucus in the very near future.

**ACTUs ABDICATE HEALTH CARE RESPONSIBILITIES?** An AIDS Clinical Trials Unit (ACTU) attempted to expel from the trial one of its patients who developed a toxic response to ddI last week. This is a case in point of what we've suspected all along; that is, that many ACTG hospitals are more than happy to accept the NIAID money for administering a trial but are often reluctant to measure up to their health care responsibility to patients enrolled in the trials. T&D would like to investigate this incident further. Any information concerning similar experiences would be appreciated.

**ALBANY II: THE RETURN.** From day one of the crisis, the state of New York has refused to shoulder its share of the financial burden. (I know, what's new.) And now, as "early intervention" and "management" increasingly become the buzz words around town, access to affordable (or better still, free) prophylaxes and treatments is absolutely a matter of life and death. As the state continues to tighten its belt, we are going to be the ones squeezed out unless we take action. Governor Cuomo is up for re-election next fall, and if we organize now, we can define the issues.

Tom Keane is one of several T&D-ers who has expressed great interest in getting an Albany action off the ground. Anyone who thinks they might be able to help out can call him at (212) 228-9842.

**DRUGS ADOPTED.** Following through on the heels of our enormously successful negotiations with Bristol-Myers, members of T&D have (with assurances of expert guidance from our seasoned colleagues, Mark and Jim) volunteered to tackle the remaining drugs/treatments on our National AIDS Treatment Research Agenda and initiate the necessary research and negotiations on their own. While there still remain a few drugs unassigned, our (tentative) list looks like this:

<table>
<thead>
<tr>
<th>Drug</th>
<th>Contact</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>ddI</td>
<td>Jim Eigo</td>
<td>(212) 533-2769</td>
</tr>
<tr>
<td>ddC</td>
<td>Peter Staley</td>
<td>505-5483</td>
</tr>
<tr>
<td>EPO</td>
<td>Mark Harrington</td>
<td>353-8430</td>
</tr>
<tr>
<td>Fluconazole</td>
<td>Scott Slutsky</td>
<td>535-2852</td>
</tr>
<tr>
<td>Foscarinet</td>
<td>Spencer Cox</td>
<td>254-7095</td>
</tr>
<tr>
<td>GM-CSF</td>
<td>Larry Kramer/Garry Kleinman</td>
<td>477-3934</td>
</tr>
<tr>
<td>Bactrin</td>
<td>David Kirschenbaum</td>
<td>(718) 636-0806</td>
</tr>
<tr>
<td>Ansamycin</td>
<td>Iris Long/Jim Eigo</td>
<td>(718) 779-6684</td>
</tr>
<tr>
<td>CD4-exotoxin</td>
<td>Mark Milano</td>
<td>no number</td>
</tr>
<tr>
<td>CD4-immunoadhesin</td>
<td>Mark Milano</td>
<td>no number</td>
</tr>
<tr>
<td>Diclazuril</td>
<td>Tom Cunningham</td>
<td>212-864-4607</td>
</tr>
<tr>
<td>Hypericin</td>
<td>Mike Barr</td>
<td>212-765-7127</td>
</tr>
<tr>
<td>Passive Immunotherapy</td>
<td>Iris Long</td>
<td>(718) 779-6684</td>
</tr>
<tr>
<td>Peptide-T</td>
<td>Jon Engbretson</td>
<td>212-691-9176</td>
</tr>
<tr>
<td>Compound Q</td>
<td>Michael Petrillus</td>
<td>no number</td>
</tr>
<tr>
<td>High-dose Acyclovir</td>
<td>Garry Kleinman</td>
<td>255-4009</td>
</tr>
</tbody>
</table>

If you have any information you think might prove helpful to these people (either about experience in other countries, about the pharmaceutical company(ies) developing the drug/treatment, or any anecdotal evidence) as they begin their fact finding and strategy formulation, please feel free to give them a call.
Josh,

Here are researchers we are promoting as our "friends".

Highest priority:

Dr. Michael Lange
St. Lukes/Roosevelt NY
212.523.2524

He's an important and much respected virologist and a critic of HIV/AZT

Next:

Dr. Rosemary Soave
NY Hospital/Cornell Medical Center

Very strong on issues related to women and AIDS, also much respected in establishment.

Third:

Dr. David Kotler
St. Lukes/Roosevelt NY

A gastro enterologist. Much respected.
Subscribe to Treatment and Data Digest

The Treatment and Data Digest is the official newsletter of ACTUP New York's Treatment and Data Committee. The Digest contains the latest information on the drugs and clinical trials that we're following and actions that we're planning. The Digest also contains the latest news from the FDA and NIH (from our highly placed sources). Recent issues of Treatment and Data Digest have included articles on the FDA's confusing stand on Immuthiol, the status of our negotiations with Lyphomed over the price of aersolized pentamidine, a discussion of the availability of a drug after a trial has ended, Hoffmann-La Roche's measly parallel track program for ddC and the protest it led to in San Francisco. Past issues of the Digest contained the first formative discussions of parallel track as well as our vision for a remodelled AIDS Clinical Trial Group.

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   New York, NY 10016
March 27, 1992

The Honorable Ted Weiss
Chairman, Human Resources and Intergovernmental
Relations Subcommittee
U.S. House of Representatives
2157 Rayburn House Office Building
Washington, D.C. 20515

Re: Hearing on Federal Response to Tuberculosis Epidemic

Dear Congressman Weiss:

As an advocate for people with tuberculosis, I am writing to provide you with information and perspectives on several critically important issues. I am enclosing copies of this letter for your fellow Subcommittee members. I am requesting that you include this letter as additional information submitted for the record of this hearing.

For over thirty years I have been a pharmaceutical chemist. I was awarded a doctorate in pharmaceutical chemistry in 1972. For most of my career I have worked in the development of medicines, and I have published over twenty articles in peer-reviewed scientific journals. Since 1987, I have been an advocate for people living with AIDS and HIV, focusing on medication development, especially during the experimental phase.

I am a member of the AIDS Coalition to Unleash Power in New York City. ACT UP is a diverse, non-partisan group united in anger and committed to direct action to end the AIDS crisis. Among ACT UP's accomplishments are years of vigorous advocacy for federal funding for AIDS research.

In October 1991, a number of concerned ACT UP members formed the Tuberculosis Working Group, which has examined a range of TB issues, including treatment of patients, the unavailability of certain TB medicines, and the importance of federal funding of TB research and health management.
Treatment Issues

TB patients and their advocates are concerned about the quality of medical treatment for TB. Medical literature is full of reports of deficiencies in tuberculosis diagnosis, treatment, prevention and care at health departments, hospitals, prisons, nursing homes, and homeless shelters. \textit{Patients and advocates suggest that such deficiencies continue to exist in part because patients and their advocates have no voice in public health agencies concerned with tuberculosis.}

Some TB patients report that their physicians failed to give them important information about their expected course of treatment and medications, and failed to keep them informed of test results and changing medications. \textit{Informed consent should be -- although it does not appear to be -- a hallmark of TB treatment. In TB, patient compliance with treatment programs are paramount for success.} Thus patients should receive complete explanations -- in language understandable to the patient and with accompanying written information sheets -- about:

- Expected course, and length of time, of treatment;
- List of prescribed medications with instructions;
- Alternate treatments available;
- Test results as they become available;
- Description of signs and symptoms of relapse; and
- Side-effects of medications.

In geographic areas with high incidences of multiple drug resistant TB, every patient should be tested for drug resistance, test results should be obtained within three weeks, and results should be given to the patient. \textit{Experts advise that all TB patients should receive individualized treatment -- such is not now the case.} Many patients receive standard treatment, which may not be effective. Unfortunately, individualized TB treatment appears to be rare.

Without early testing for drug resistance, some patients will not receive effective treatment and their diseases will progress, and other patients will develop further drug resistance.

According to patient advocates, there are almost no non-governmental agencies supplying TB education, standard of care guidelines, and social services to patients.
Our experience with AIDS shows that progress against disease can be quicker, government at all levels can be stimulated, and resources can be more readily obtained when patients share responsibility for their treatment and have input into research. Patients with tuberculosis must have access to counseling, to child care, and to support groups like people with other diseases. In New York City, there are no community-based service organizations for people with tuberculosis. Public clinics and hospitals have no place to send patients who need help. The government points to the American Lung Association and its affiliates to carry out advocacy programs for people with tuberculosis.

People living with AIDS and their advocates have proven the value of patient and patient advocate participation in research, public health policy-making, public education, decision-making about financing community-based patient service and health care, and the organization of clinical trials of experimental drugs. We think that TB patients and their advocates should be encouraged to accept comparable roles at local and national levels.

Dr. Michael Iseman, a nationally recognized expert in TB treatment, recently recommended that a clinical trial of the four-drug regimen be conducted on newly-diagnosed patients in New York City, because of the City's large number of new TB cases. Advocates for people with TB agree. Expertise should be gained on the treatment, clinical management, and individualized chemotherapy for patients with TB.

Unavailable TB Medicines

Two major drugs are used together to treat TB: INH (isoniazid) and rifampin. These drugs are effective treatments in patients whose TB is not drug-resistant. Since drug resistance cannot be predetermined, three adjuvant drugs are used: Streptomycin, pyrazinamide, and ethambutol. Seven other medications are available for use when TB is found to be resistant to INH and rifampin. The use of TB drugs is generally restricted to TB, lest they become ineffective against TB because of overuse for other illnesses.

Two drugs -- streptomycin and para amino salicylate sodium (PAS) -- used to treat TB have been unavailable in the United States. Streptomycin is widely used against TB worldwide and is an adjuvant to the major drugs used against multiple drug resistant TB. There have been shortages of several other TB drugs. Lack of these drugs has contributed to the increasing incidence of multiple drug resistant TB.
Any one of the twelve TB drugs once approved for marketing in the U.S. could disappear due to lack of domestic manufacturers. Why has the Federal Government failed to ensure the availability of TB drugs?

Current FDA and CDC plans call for the CDC to purchase foreign-made streptomycin and PAS and make them available to patients as investigational new drugs. Physicians do not see the necessity for classifying drugs in clinical use for over forty years as investigational. What is the basis for classifying streptomycin and PAS as investigational? Is this medically unnecessary classification required by statutes or regulations?

When domestic manufacture of streptomycin and PAS resumes, their manufacturers will reportedly seek "orphan drug" designations, since there are now fewer than 200,000 patients in need of these drugs. Thus the domestic manufacture of these drugs will become more financially feasible. As the rest of the TB drugs become financial losers for their manufacturers, can we expect the cycle of abandonment of domestic production, shortages, more than a year of unavailability, a period of reclassification as "investigational," "orphan drug" designation, domestic "investigational drug" classification, and then resumption of domestic manufacture?

In addition to the disappearance of streptomycin and PAS in the United States, a combination tablet containing INH, rifampin, and pyrazinamide (Refater), has never been available in this country, although it is sold in other countries, and it is produced by an American company, Marion Merrell Dow, Inc. The company has been asked to start manufacturing of the combination drug, but they must submit an NDA to the FDA for approval. There is not date proposed as to when the drug will be available for pre-marketing distribution or sale in the U.S. Patients in clinical trials using the combination tablet had higher conversion rates (a measure of recovery) than those who used the three drugs separately.

It makes no sense that such a combination tablet for a disease with which patients have difficulty taking medications as prescribed is not available in this country. TB patients complain of having to take too many tablets and capsules, some of which are large enough to stick in their throats. Some patients with MDR TB may have to take medications several times per day, totalling as many as over 40 capsules and tablets per day.
Federal Funding Issues

It has been suggested that the current upsurge in TB is linked in large part to the AIDS epidemic. People with HIV disease and their advocates are concerned that they will be blamed for the TB epidemic, and that this excuse will be used to make to take funds from AIDS research and services in order to meet the current TB crisis. We and many others, feel that AIDS funds should not be used for TB. AIDS research funds have essentially already been cut for the next fiscal year.

TB research and services should be adequately funded without taking any of the funds for AIDS. The vast majority of people with TB disease people do not have HIV disease.

Recent studies have revealed that the quality of the TB control programs varies greatly. Many local TB control programs appear to be inadequate for the people they must serve. Does the CDC help define standards of care for patients with tuberculosis? Does the CDC study or enforce such standards in state and city health departments? How can standards of care be maintained in local programs? How can the public and health care advocates monitor the activities and quality of these programs?

Experts appear to disagree about the best treatment regime for tuberculosis. With the Denver regimen, patients received medicines twice a week, including injections of streptomycin. With the Hong Kong regimen, medications are given three times a week, also including injections of streptomycin. On the other hand, the CDC recommends daily dosages of oral TB medications, not including streptomycin. On what factors are the CDC's daily treatment recommendations based? Are there any financial considerations involved in the CDC's daily treatment recommendations? Is daily treatment the best approach, particularly where it is difficult to monitor patients, and where patients do not adhere to their prescribed regimen?

In early 1989, the CDC published "A Strategic Plan for the Elimination of Tuberculosis in the United States." In the Plan's appendix entitled "Planning Assumptions," the responsibilities of state and local health departments, and of the Federal Government, were outlined. Fulfilling the specified responsibilities would easily have cost one hundred million dollars per year. Yet only a tiny fraction of needed funds were ever appropriated and spent. Why has government at all levels been allowed to abandon its responsibilities for TB prevention, treatment, and research?

* * *
Please know that I appreciate the continued attention shown to the problems of people living with AIDS, and with TB, by the members and staff of the Subcommittee.

Please do not hesitate to contact me if I may provide more detailed information on the topics discussed in this letter.

Sincerely,

Iris L. Long, Ph.D.,
for the Members of the Tuberculosis Working Group
March 31, 1992

Iris L. Long, Ph.D.
Tuberculosis Working Group
ACT UP
84-09 35th Avenue
Jackson Heights, N.Y. 11372

Dear Dr. Long:

I am writing to thank you for the questions and letter you prepared on behalf of the members of the ACT UP Tuberculosis Working Group. The letter will be distributed to all members of the subcommittee in their hearing folders.

I found the questions and letter to be useful and on target. Many of the subjects you raised will be included in the questions I will ask the Administration's representatives.

Again, thank you for your contribution to this hearing and this crucial issue. I hope to continue to work with you on the right to appropriate health care and treatment for all who need it.

Sincerely,

TED WEISS
Chairman

TW:pf
Today the subcommittee is examining the resurgence of tuberculosis in America as an even more deadly killer than it was in the middle of this century -- thirty to forty years ago.

In the 1940's science gave us the tools to prevent tuberculosis from developing even in infected persons, and also to treat those who have active TB. So why, after decades of control, are we now failing the American public?

It is no secret why TB is flourishing. It is for the same reasons that TB raged through our nation decades ago -- poverty and its allies -- malnutrition -- poor health care -- and crowded living conditions.

That the government would permit TB to reemerge in this day and age is nothing less than an outrage. As we will see today, while TB cases grew in number over the past decade, funds dwindled. The government has had its head in the sand -- as it did in the early years of the AIDS epidemic.

But there are enormous differences between TB and HIV. First, TB could have been prevented and it can be cured. But secondly, TB is transmitted through casual contact, and it is spreading to hospital workers, migrant workers, prisoners, prison guards, AIDS patients, school children, workers on cruise ships and patients waiting in emergency rooms for treatment for other conditions.

The tragedy of this epidemic is that we had it under control. But then we dropped the ball. We let the programs that defeated TB run out -- unfunded, unattended. We grew to accept a small number of TB cases -- among poor people, mostly minority. To them, Washington turned its back -- confusing TB with "too bad."
The tuberculosis epidemic is a matter of extreme urgency. The cost of finding and treating persons with TB now will be small compared with the cost of our failure to act.

When will we learn that we cannot ignore the health of our poor and disenfranchised citizens. The resurgence of TB is an indictment of public health in America which continues to be crisis-driven. We can put tuberculosis back in the history books where it belongs if we have the will and provide the funds.

Our first panel today is composed of experts involved in various aspects of the TB epidemic -- an infection control specialist, a researcher, a pediatrician, and a clinician. Then we will hear from three experts from the Administration who have responsibility for programs, policies and funds that can be employed for the battle against tuberculosis.
Dear Congressman Weiss:

Over the last three years, I have testified before the Subcommittee, met with you, and been consulted by your staff on AIDS issues. I am volunteering -- and requesting -- to testify at your hearing on the federal response to the tuberculosis epidemic. I have spoken to Patsy Fleming about my offer and request.

I was impressed that your press release of March 12th demonstrates your grasp of important TB issues. I believe the hearing will present the fairest and most realistic picture of the current situation and prospective solutions if you invite witnesses representing differing perspectives.

For the last five months, I have been focusing on issues raised by the increasing incidence of TB, and of TB's relationship with HIV disease. I hope you will find the following suggested questions, topics for discussion, and potential witnesses useful in your hearing.
The Honorable Ted Weiss

March 20, 1992

Examining the Federal Response to the Tuberculosis Epidemic

As you know, ACT UP was founded in New York City, now has chapters across the country and throughout the world, and has made continuing contributions to progress against AIDS on a broad spectrum of issues. ACT UP has made particular contributions to patient issues in clinical trials of experimental medicines, and to mechanisms for making such medicines available to patients outside trials.

Since late 1991, ACT UP's Tuberculosis Working Group has been examining various issues raised by the TB epidemic. Members of the Group include people active with the homeless, prisoners, and drug users. We have aided patients in obtaining the TB drugs streptomycin and PAS. We have educated ACT UP's membership about TB. Over 300 hundred letters have been sent to Dr. James O. Mason, Assistant Secretary for the Health & Human Services, calling for federal leadership and funding for a TB prevention, treatment, and research program. A copy of the letter is enclosed.

Below are 27 questions that we would like to ask at the upcoming House Panel to Examine Federal Response to Tuberculosis Epidemic.

Questions concerning Patient Treatment, Services, Advocacy, and Empowerment

1. TB patients and their advocates are concerned about the quality of medical treatment for TB. Medical literature is full of reports of deficiencies in tuberculosis diagnosis, treatment, prevention and care at health departments, hospitals, prisons, nursing homes, and homeless shelters. Patients and advocates suggest that such deficiencies continue to exist in part because patients and their advocates have no voice in public health agencies concerned with tuberculosis. How would you propose that patients and advocates gain a voice in the decisions of your agency and of local health departments?

2. Patients with TB and HIV/TB diseases are receiving standard treatment without informed consent. Patient advocates believe that there should be individualized treatment which is the most effective and save for that patient, this is rarely done although expert advise it. How would you propose that patients gain a voice at all level of medical establishment?
3. Patient advocates say that there are almost no non-governmental agencies supplying TB education, standard of care guidelines, and social services to patients. To your knowledge, what agencies in this country provide such services?

4. Our experience with AIDS shows that progress against disease can be quicker, government at all levels can be stimulated, and resources can be more readily obtained when patients share responsibility for their treatment and have input into research. Patients with tuberculosis must have access to counseling, to child care, and to support groups like people with other diseases. In New York City, there are no community-based service organizations for people with tuberculosis. Public clinics and hospitals have no place to send patients who need help. The government points to the American Lung Association and its affiliates to carry out advocacy programs for people with tuberculosis. What do you know of the American Lung Association's programs providing services to TB patients?

5. Are the state and local programs of the American Lung Association, and of other voluntary/professional agencies, evaluated regularly by the CDC or other organizations? What recommendations have been made to strengthened such programs?

6. People living with AIDS and their advocates have proven the value of patient and patient advocate participation in research, public health policy-making, public education, decision-making about financing community-based patient service and health care, and the organization of clinical trials of experimental drugs. What steps should be taken to encourage TB patients and their advocates to accept comparable roles in the formidable efforts required by the TB epidemic?

Questions for Dr. Anthony Fauci and Dr. William Roper

7. Dr. Fauci and Dr. Roper: Two drugs -- streptomycin and para amino salicylate sodium (PAS) -- used to treat TB have been unavailable in the United States became unavailable last year. Streptomycin is widely used against TB worldwide and is an adjuvant to the major drugs used against multiple drug resistant TB. There have been shortages of several other TB drugs. Lack of these drugs may have been a contributing to the increasing incidence of multiple drug resistant TB.
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8. Dr. Fauci and Dr. Roper: Dr. Lenoid B. Heifets, a noted pharmacology expert in mycobacterial diseases, working at the National Jewish Center for Immunology and Respiratory Medicine, Denver, Colorado, has develop techniques to individualized chemotherapy from the very beginning of patient treatment. Advocates and TB experts believe that individualized chemotherapy should be initiated in New York City immediately, where the resistance to major drugs is so high that many patients will not be cure because they are being treated with ineffective drugs. How would you propose that individualized chemotherapy treatment be implemented? What plans does your agency have to implement individualize TB chemotherapy?

9. Dr. Roper and Dr. Fauci: In early 1989, the CDC published "A Strategic Plan for the Elimination of Tuberculosis in the United States." In the Plan's appendix entitled "Planning Assumptions," the responsibilities of state and local health departments, and of the Federal Government, were outlined. Fulfilling the specified responsibilities would easily have cost one hundred million dollars per year. Yet only a minute fraction of needed
funds were ever appropriated and spent. Why has government at all levels been allowed to abandon its responsibilities for TB prevention, treatment, and research?

10. Dr. Roper and Dr. Fauci: What progress has been made toward the elimination of TB in this country since the "Strategic Plan" was published? Is this an "ideal world" plan, or did the planners recognize the "real world" situation? Is the public lulled into a false sense of security by the existence of the "Strategic Plan?" How large a budget would be adequate to carry out the "Strategic Plan" over the next five to ten years?

11. Dr. Roper and Dr. Fauci: Tuberculosis is a curable disease -- given trained physicians, a supportive public health infrastructure, proper diagnosis, laboratory services, medications, treatment, research, and patient services. In 1984, the number of reported cases of newly-diagnosed TB fell to the lowest point in U.S. history. The argument may plausibly be made that TB has rebounded because public health authorities became complacent, tolerating levels of TB in certain populations -- including immigrants, the poor, Latino/as, and Blacks. Now, in 1992, TB shows up in other populations as prisoners, drug users, and the homeless. Will tolerance of certain levels of TB in these populations guarantee that TB will not be eliminated in the United States?

12. Dr. Roper and Dr. Fauci: It has been suggested that the current upsurge in TB is linked in large part to the AIDS epidemic. People with HIV disease and their advocates are concerned that they will be blamed for the TB epidemic, and that this excuse will be used to make to take funds from AIDS research and services in order to meet the current TB crisis. Is the concern about AIDS funds be used for TB justified? What is the likelihood of adequate funds being made available for tuberculosis while increasing funding for AIDS research and services?

13. Dr. Roper and Dr. Fauci: The Federal Government has developed effective mechanisms to respond quickly and wage war when foreign enemies jeopardize the lives or safety of our citizens. Why has the Federal Government not taken a more militant approach to disease control? Should realistic rapid response mechanisms be developed to respond to public health emergencies posed by infectious diseases?
Questions for Dr. Fauci

14. Dr. Fauci: Advocates for people with TB are saying that NIAID must shoulder partial blame for the current TB crisis because NIAID's tuberculosis program has been haphazard, low priority, and uncoordinated. In FY 1991, NIAID made only a handful grants with direct implications for the control of mycobacterium tuberculosis disease. Can you explain the history of NIAID's tuberculosis program, and the history of NIAID's collaboration with the CDC on tuberculosis, and on TB's relationship with HIV disease? How soon can the public look forward to a truly coordinated program?

15. Dr. Fauci: Part of the AIDS clinical trial program deals with opportunistic infections. Extrapulmonary TB is an AIDS-defining disease. Report within the U.S. have shown that significant numbers of people with HIV disease have had TB. Why did the ACTG program sponsor no clinical trials for the treatment of TB? Why has NIAID not responded more quickly to epidemiological reports indicating that TB would become a major problem?

Questions for Dr. Roper

16. Dr. Roper: Dr. Michael Iseman, a nationally recognized expert in TB treatment, recently recommended that a clinical trial of the four-drug regimen be conducted newly-diagnosed patients in New York City, because of the City's large number of new TB cases. Do you see such a trial being conducted in the near future, and which agency would sponsor the trial, NIAID or the CDC?

17. Dr. Roper: Definitive regimens for the effective treatment of TB, and multiple drug resistant TB, in people with HIV disease have yet to be developed. When can we expect clinical trials of regimens to treat TB in people with HIV? Would any of these trials be conducted in New York City?

18. Dr. Roper: Why did the CDC decide not to include pulmonary TB as an AIDS-defining disease? Is there a medical rationale for separating AIDS and pulmonary TB? Was there a concern that designating TB as AIDS-defining would inappropriately enlarge the population entitled to priority medical services?
19. Dr. Roper: Why was the CDC program for monitoring the development of mycobacterial resistance de-funded in 1986? The CDC, a national guardian of the public health, became blind to the ensuing MDR-TB epidemic. Did other TB programs lose funding in the mid-1980s?

20. Dr. Roper: Recent studies have revealed that the quality of the TB control programs varies greatly. Many local TB control programs appear to be inadequate for the people they must serve. Does the CDC help define standards of care for patients with tuberculosis? Does the CDC study or enforce such standards in state and city health departments? How can standards of care be maintained in local programs? How can the public and health care advocates monitor the activities and quality of these programs?

21. Dr. Roper: Public officials have explained their failures to take adequate steps to prevent the transmission of TB in hospitals by stating that they cannot recommend large expenditures without accepted CDC guidelines for such measures as ventilating units, biological filtration units, and ultraviolet lights. Does the CDC plan to develop such guidelines? When may we expect final promulgation of such guidelines?

22. Dr. Roper: Recently, an estimate of $250 million was made for work and equipment necessary upgrade infection control mechanisms in Bellevue Hospital in New York City. What level of government can be expected to pay for hospital infection control upgrading? Should such funds be appropriated under the federal Hill-Burton Act?

23. Dr. Roper: Will the CDC promulgate infection-control guidelines for institutions such as jails and prisons, congregate and small-group homeless shelters, and nursing homes? When may we expect such guidelines? Are there any plans for federal oversight or enforcement of institutional infection-control?

24. Dr. Roper: In the medical literature on TB treatment, experts describe several different TB treatment regimens. Examples include the Denver regimen, the Hong Kong regimen, and the CDC regimen-trial 21. How can the public be assured that local TB control and treatment programs do an adequate job of:

(a) treating patients,
(b) completing timely drug-susceptibility tests,
(c) keeping adequate patient records of treatment,
(d) ensuring that patients complete therapy, and
(e) notifying those who have been exposed to TB?

25. Dr. Roper: Experts appear to disagree about the best treatment regime for tuberculosis. With the Denver regimen, patients received medicines twice a week. With the Hong Kong regimen, medications are given three times a week. On the other hand, the CDC recommends daily dosages of oral TB medications. On what factors are the CDC's daily treatment recommendations based? Are there any financial considerations involved in the CDC's daily treatment recommendations? Is daily treatment the best approach, particularly where it is difficult to monitor patients, and where patients do not adhere to their prescribed regimen?

26. Dr. Roper: Have the CDC's past collaborations in international TB programs produced any results?

Suggested Witnesses

Charles Ahlers, Former President, Queens (New York City) Lung Association, (718) 263-5656. Dr Ahlers could give prospectives of the history of TB infection in New York City from an advocate point of view.

Karen Brudney, M.D., Columbia Presbyterian Hospital, New York City Department of Health.

David L. Cohn, M.D., Expert in Mycobacterial Diseases in HIV Disease, National Jewish Center for Immunology and Respiratory Medicine, Denver, Colorado.

George W. Comstock, M.D., Johns Hopkins University Medical School, Chairman of the Advisory Committee (to the U.S. Secretary of Health and Human Services) for Elimination of Tuberculosis.
Larry Geiter, M.D., Acting Chief, Clinical Research Branch, U.S. Centers for Disease Control. Dr Geiter can give information on how the CDC conducts clinical trials.

Gail Gerena, M.D., Chest Clinic, Bellevue Hospital, New York, (212) 561-6386. Dr Gerena has a vast experience with patients with multi-drug resistant TB and other complications.

Margaret Hamburg, M.D., Acting Commissioner of Health, New York City.

Michael D. Iseman, M.D., Chief, Clinical Infectious Disease, National Jewish Center for Immunology and Respiratory Medicine, Denver, Colorado.


Kenneth Ong, M.D., Deputy Commissioner of Health, New York City.
ACT UP

AIDS Coalition To Unleash Power

April 12, 1992

TUBERCULOSIS FACT SHEET

Why are AIDS activists turning their attention to Tuberculosis?

In October 1991, members of the AIDS Coalition to Unleash Power (ACT UP) in New York City formed its Tuberculosis Working Group (TBWG) in response to the TB crisis here. Activists were reacting to outbreaks of pulmonary TB and fatal MDR TB among patients with HIV disease. They were also reacting to complaints from New York City TB patients about ineffective and unavailable medications, inadequate resources and high mortality of people with HIV disease or AIDS.

What problems have AIDS activists identified in public health efforts against TB?

1. The public health system is unable to respond promptly and effectively to the current upsurge of TB cases and the clear threat of a continuously increasing TB caseload. In New York City, hard hit by pulmonary and extrapulmonary TB and MDR TB, some physicians, because of the lack of information, do not view the situation as a particular problem. Nationally recognized TB experts, and officials of the Food and Drug Administration (FDA), the National Institute of Allergy and Infectious Diseases (NIAID) and the Centers for Disease Control (CDC), recognize the seriousness of the epidemic. According to one CDC official, the lethargic response to TB and the rise in MDR TB shows the decay of state and city tuberculosis control infrastructure over the last decade. Activists have concluded that the blame should be placed on government officials at both levels of public health, national and local.

2. From the patients' point of view, the inadequate response to TB means that:

   -- Patients with multi-drug resistance to major TB medications are extremely difficult to identify and treat (ALMOST IMPOSSIBLE IN THE HIV INFECTED) because there are no resources, such as extended hospital care or well-trained physicians or laboratories equipped to conduct drug sensitivity tests;

   -- Patients with pulmonary TB may remain for months to be infectious, thus exposing others -- including their family members -- to all forms of TB;

   -- Little or no effort is made to trace contacts of people with TB or to provide preventive treatments for those exposed to TB;

   -- Because people with HIV may be unreactive to the standard TB test (PPD) and often have abnormal respiratory symptoms, their physicians often overlook TB as a diagnosis;
Patients do not receive adequate information about TB, its treatment and diagnosis, tests for drug resistance, their own specific medications, and the consequences of not completing treatment. Directly-observed treatments (DOT), an accepted treatment modality the world over, are available only to a few of the patients who need them. Even if DOT were available to all patients it would not work without well-trained physicians, extended hospital care, individualized treatment and equipped labs.

3. Government officials recognize that the U.S. may lose any of the twelve medications used mainly to treat TB -- because drug companies are abandoning domestic manufacture of these drugs. Already the U.S. has lost two drugs -- streptomycin, an important adjuvant to the two principal TB drugs, and PAS (para amino salicylate sodium). Streptomycin is used to treat both TB and MDR TB; PAS is used to treat MDR TB.

Officials at the FDA and CDC are planning to import streptomycin and PAS and make them available under investigational new drug (IND) protocols in April 1992, but there will be a limited supply of these drugs It remains to be seen whether the whether the CDC's IND distribution system will get the medicines to all who need them. The longer-range plan is to encourage resumption of domestic production of these drugs, but so far there have been no guaranteed results.

Additionally, the CDC and FDA are encouraging domestic manufacture of Rifater, a three-in-one combination tablet containing rifampin, INH, and pyrazinamide. Studies have shown that patients on the combination tablet have higher rates of conversion to negative culture following prescribed treatment than those on separate medications.

4. In order to quell the anxieties of HIV-positive people about TB and MDR TB, CDC officials cite the results of preliminary studies as evidence that TB is a curable disease among people with HIV. Yet recent medical literature indicate that MDR TB is considered incurable in HIV infected persons.

5. Federal TB research spending has ranged from $323,000 in 1979 to $3,607,516 in 1991, and has focused on basic research on TB. Little research has been done on TB treatments or diagnostic tests. Against this background, Dr. Anthony Fauci of the National Institute of Allergy and Infectious Disease (NIAID) recently proposed a TB treatment research project which would take several years and cost several hundred million dollars. For 1992-93, the President's TB budget, including research, proposes spending $66 million.

AN EMERGENCY NATIONAL AGENDA FOR TUBERCULOSIS:
MEDICAL AND PUBLIC HEALTH MANAGEMENT, AND RESEARCH

The current TB epidemic is a national public health emergency which must be addressed immediately. Certainly new drugs and diagnostic tests for TB must be developed, but we cannot wait for or depend on future discoveries. We must use the resources close at hand.

1. The Federal Government Must Assume Leadership and Financial Responsibility for Public Health Management of TB. In 1989, after several years of study, the CDC published "A Strategic Plan for the Elimination of Tuberculosis in the United States." A reasonable plan on which there is consensus does exist, although only a tiny fraction of the funds needed to implement the plan have been spent. State and local governments have been responsible, historically, for TB prevention and control efforts. Today these governments will not readily accept financial responsibility for the work which must be done. Turf wars between local agencies are now taking place. Thus the federal government must fund and manage a national program of TB prevention and treatment.

2. Starting with New Tuberculosis Programs, New Mechanisms for Public Oversight of Medical Research Efforts Must Be Developed. People living with AIDS and their advocates have established a participatory presence in AIDS research at every level. Yet these advocates lack the background, funding, and resources to monitor research and publicize their findings. Even Congressional oversight committees, with the resources at their disposal, have proven inadequate at ensuring effective allocation and management of federal research funds.

3. The Federal Government Must Develop and Implement a Program to Educate Physicians and Other Health Care Professionals about the Diagnosis and Treatment of Tuberculosis. New medical centers of excellence must be established.

4. A Federal Agency Must Maintain and Monitor Stocks of Existing TB Medicines. Any TB treatment initiative with a chance of success will require the availability of all medications demonstrated effective against TB. One TB medicine, streptomycin, is unavailable in the U.S. in part because the process of its foreign manufacturer failed to meet FDA standards. Yet patients in Canada and throughout Europe are receiving streptomycin as manufactured. Since TB is an international problem, international standards for the manufacture of TB medications should be agreed upon, in order to meet standards wherever needed.

The CDC does not appear to know how to do maintain adequate stocks of TB medicines. Existing TB medicines will be needed for year to come; and the nation's health requires that they be manufactured in the United States from all domestic materials. Until recently, the federal government provided no leadership in this area. In the absence of dependable profits, drug companies cannot be expected to respond to the national's public health needs without federal stimulus.

5. A Federal Agency Must Examine TB Medicines and Diagnostic Tests Used Successfully Outside the United States. Thiacetazone and sparfloxacin, are drugs used to treat MDR TB, have not been used in the U.S. Rifater, a three-in-one combination tablet, has been used outside the U.S. and, according to studies, significantly aids patients in following prescribed drug therapies.

6. Better and More Rapid Diagnostic Tests and Procedures, and More Effective Patient Management Programs, Must Be Developed. For lack of good diagnostic tests, patients go undiagnosed and untreated, and spread TB. Networks of reference laboratories, and standards for all laboratories conducting mycobacterial tests must be developed together with training and educational programs for laboratory personnel.
7. The CDC must monitor and report on cumulative prevalence and incidence rates of TB and MDR-TB in all communities where rate is high. The types of survey conducted by the CDC must be increased in these areas: evaluation of mycobacterial diagnostics, drug susceptibility testing, effectiveness of case reporting and contact tracing, patient compliance with therapy, and access of patients to TB drugs.

8. The CDC and NIAID separately fund clinical trials testing TB regimens. The CDC and NIAID should collaborate better on the design and management of clinical trials for testing TB therapies for treatment and prophylaxis putting aside historical turf issues. Turf wars between agencies must stop.

9. At clinical trial or demonstration project sites supported by the CDC, Community Advisory Boards (CABs) composed of members of tuberculosis and AIDS communities must be established. Current and future efforts against TB, including research programs, should include participation by TB patients, their advocates, and concerned members of the public.

10. Clinical trials and demonstration projects to test medications in both HIV positive and negative patients with MDR TB must be implemented. Individualized treatment protocols for all MDR-TB patients must be developed and achieved.

11. Clinical trial information and other treatment information must be more accessible quickly to the tuberculosis and AIDS communities and professional communities. Advocates for people with TB must be participating members of local and national councils.

12. Members of the AIDS Clinical Trial Group (ACTG) must become involved with the problems concerning the escalating rates of tuberculosis such as treatment, prophylaxis, medical care and funding issues at the national, state and local level.

13. Hearings and public forums must expose the facts of TB epidemic, and educate the public and legislative representatives. In part, the resurgence of TB is a product of a public health TB control effort which deteriorated in the absence of public attention.

CONTACTS: David Samuels 212 932-1318; Iris Long, Ph.D. 718 779-6684, Tuberculosis Working Group (Distributed at The Fourteenth AIDS Clinical Trials Group Meeting -- Wash D.C., April 12, 1992)
DEMAND FOR THE BARBARA MCCLINTOCK PROJECT TO CURE AIDS
Working Document proposed by Congressional Working Group, ACT UP/NY
17 December 1992

The present U. S. AIDS research effort is incapable of bringing the AIDS crisis to an end.

- The organization, structure and processes have been a profound barrier to the testing of divergent hypotheses, the prime tenet of quality scientific research. Therefore, basic AIDS research has been greatly inhibited.
- Conflicts of interest at the National Institutes of Health (NIH) make it necessary to create a new project, the sole purpose of which is to find a cure for AIDS and to separate it financially and conceptually from the universities and pharmaceutical companies.
- Twelve years into the epidemic, both governmental and private AIDS research is still criminally slow, disorganized and unproductive.

Therefore, the federal government must take extraordinary steps to remove all barriers to develop cures. President-elect Clinton has called for a "Manhattan Project for AIDS". ACT UP demands that Congress enact legislation to implement such an all-out effort as follows:

I. A declaration of the dire urgency of the international AIDS pandemic and the need for immediate, rapid, focused steps towards curing AIDS.

II. The establishment of a new Barbara McClintock Project to Cure AIDS, jurisdictionally separate from the National Institutes of Health (NIH) and reporting to (but not overseen by) the President through the "Special Assistant on AIDS". The Project shall have the following mandates:

1. The Project's goal will be to find a cure for AIDS, with cure being defined to include "any and all approaches which will restore the immune system and ensure a normal life span with a reasonable quality of life". To that end, it will have two missions:
   a. to pursue any and all basic science investigations, based on diverse theories and schools of thought which elucidate the pathogenesis of AIDS,
   b. to identify, based on this work, all new promising cures and to oversee their timely and adequate testing through the extraordinary powers detailed in section 4 below.

2. In order for the Project to achieve its goals, its work must be carried out in the most efficient and cooperative manner possible, free of private interests and bureaucratic red tape. To this end,
   a. The Project shall establish one central location for its work. All primary research staff will work at that location; contributing researchers located around the world will interact via teleconferencing, an international computer network, and regularly scheduled face-to-face meetings.
   b. All primary research staff and administrators shall be financially compensated only by the Project and may not have conflicts of interest with private organizations (including but not limited to universities, pharmaceutical companies, private research organizations, etc).

\* Barbara McClintock was a research geneticist who, bucking the then-prevailing orthodoxy, discovered the premises underlying DNA replication, a crucial breakthrough in basic biology. Her approach, an intense commitment and a focus on divergence rather than the norm, should be a model for AIDS research.
c. The Project shall be funded by public - not private - monies.

d. People with HIV and people with AIDS from all affected communities and their advocates shall play an active decision-making - not merely advisory - role in the development, structure and functioning of the Project.

e. The Project shall, in addition to basic research investigations, operate an on-site clinic to conduct small scale research trials with human participants if such trials are crucial for testing hypotheses related to its basic research.

3. To ensure that most open and productive research paths be pursued and produce a cure accessible to and usable by all affected people:

a. Equal consideration shall be given to allopathic and other medical approaches and scientific theories, and researchers representing divergent approaches shall be on the primary research staff as well as be contributing researchers.

b. All people with HIV and people with AIDS must be included in understanding the disease, its production and development. The differences among people must be considered central, not the similarities or "norms".

c. Information generated by the Project will be made freely available to researchers, healthcare providers, people with HIV and people with AIDS and their advocates as soon as it is available, without being inhibited by professional publication concepts.

d. Curatives ultimately released due to Intramural Project research shall not result in financial gain to any private organization and shall be made available to all affected people regardless of ability to pay.

4. In order to accomplish its goals, the Project shall have extraordinary powers to:

a. direct the utilization of any and all existing U.S. Government funded research entities and their facilities to clinically test promising cures developed on the basis of its research and to direct the manner in which such research shall proceed including staff, participants, location and timing. Such research will be funded by the McClintock Project.

b. obtain - with just compensation - samples of all potential curatives and all data regarding their development (including safety and efficacy data), as well as all other information deemed crucial to the Project.

c. exercise the right of eminent domain to:

i. implement clinical testing for potential curatives under development by private companies unless said companies adhere to an approved time frame and are forthcoming with their data as such work proceeds.

ii. use existing pharmaceutical company facilities (with just compensation) for the production of promising curatives to be utilized in McClintock Project research and, if effective, to produce such curatives in sufficient amounts to be disseminated to all people needing them.
Glossary for Barbara McClintock Project to Cure AIDS

Barbara McClintock: a research geneticist who, bucking the then-prevailing orthodoxy, discovered the premises underlying DNA replication, a crucial breakthrough in basic biology. Her approach—intense commitment and a focus on divergence rather than the norm—should be a model for AIDS research.

Pathogenesis: the origination and development of disease.

Cure: any and all approaches which will restore the immune system (including but not limited to antiretrovirals, curative vaccines and immunoregulators) and ensure a normal life span with a reasonable quality of life.

Primary research staff: McClintock staff that will be located at the central location designated for the Project.

Contributing research staff: Researchers and scientists who will be participating as consultants for short periods of time and who are not located at the central location for the Project.

Eminent domain: the power of the state to take private property for public use with payment of compensation to the owner.

Extraordinary powers: The right of the Project to engage in activities relevant to its goals which are not usual for a research endeavor but which have been used previously in special circumstances (i.e. wartime).

Manhattan Project: Crash program during World War II to build the atom bomb. The scientists were relocated to Los Alamos, New Mexico for the Manhattan Project. It was highly secretive and compartmentalized, had the complete backing of the President and Secretary of War an excess to unlimited funds.
THE ACT UP/NY WOMEN AND AIDS BOOK GROUP

Announces...

WOMEN, AIDS & ACTIVISM

Available in July 1990
The average woman in the United States with AIDS will die within six months of diagnosis. The average man will live six times longer. Women, AIDS & Activism, produced by AIDS activists, not only reveals the context for this discrepancy — social, economic, and political patterns of racism, classism, sexism, and heterosexism — but also lays out a strategy for change. From grassroots safe sex education to issues of access to resources, to challenging the government to include women’s interests, Women, AIDS & Activism goes beyond looking at AIDS as solely a medical crisis.

The volume also contains critical and groundbreaking medical information. Nine years into the AIDS epidemic The Centers for Disease Control still maintains no specific categories of findings on the behavior of HIV in women’s bodies. Women, AIDS & Activism looks at the research and asks the questions the medical/research establishment has ignored: for example, what is the connection between the rise in cervical cancer and HIV? Without asking the right questions, you won’t get life-saving answers.

Nowhere else is all the information in Women, AIDS & Activism available. With informative discussion of safer sex and sexuality, HIV testing, treatment and drug trials, public policy and activism, this is the only thorough and up-to-date analysis of AIDS issues for women. Looking at issues specific to lesbians, heterosexuals, bisexuals, prostitutes, intravenous drug users, teenagers, mothers, pregnant women, and women in prisons, this book is essential reading for everyone concerned about women’s health and the AIDS crisis.
Excerpts

Epidemological statistics do not account for all AIDS cases. Many women are diagnosed with HIV infection only after they are dead. Since the CDC has not changed its definition for AIDS, women who die of an opportunistic infection before they are even considered eligible for an actual AIDS diagnosis are excluded from the total statistical picture—that is, they not only won’t get counted but they won’t get treated: they won’t qualify for health benefits, child care, rent subsidies, or other support services.

From “What the Numbers Mean” by Risa Denenberg

Lesbians are not an isolated community: there are lesbians who shoot drugs and share needles, there are lesbians who have been married, who have babies, who are in prisons, who have sex for money, who get raped. When examining the AIDS epidemic, it becomes obvious that stereotypes are useless: it’s not who you are that puts you at risk, it’s what you do.

From “Lesbians in the AIDS Crisis” by Zoe Leonard

About the fourth or fifth woman said, “I’m here because I have AIDS.” There was an intense silence. It was the first time anyone had said that aloud in a group. By the end of the meeting, several more women had said that they were HIV-positive. Breaking the silence, the faith that it took, and the trust it built was really how ACE started.

From “Prison Issues and HIV” by AIDS Counseling and Education at Bedford Hills State Prison for Women, New York
What’s happening now is that the big established AIDS groups are going to the small ones under the pretext of working together and learning about “minority outreach.” In practice, they end up ripping off their ideas and getting big grants based on their longer track records and their experience with the funding establishment.

From “Cultural Sensitivity In Practice” by Yannick Durrand

So I made an appointment with the Beth Israel Infectious Disease Clinic. And they sent me to the neurologist and the rheumatologist and the GYN and the Hospital of Joint Diseases, and every last one of them had a different approach to what was going on with me.... I had to apply through a social worker for welfare. Suddenly, here I am, from making $30,000 a year, having a good job, to being totally caught up in the bureaucracy, of trying to get money for my son and myself.

From “Fighting for My Life” by Melinda Singleton

ACT UP is a true coalition. Everyone puts up with what my mother would call everyone else’s mischigas — craziness. I have come to appreciate what each person can and will contribute because they share a commitment to the saving of lives.

From “AIDS and Politics: Transformation of our Movement” by Maxine Wolfe

Women, AIDS, and Activism also contains a glossary, a national resource list, and annotated video and print bibliographies.
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A Spanish edition will be available in Fall, 1990.

Free to women in prison.
AIDS DOESN’T DISCRIMINATE—OUR GOVERNMENT DOES!

The HHS and the FDA must be held accountable for the exclusion of women and people of color from access to treatment and drug protocols.

FACTS/REALITY:

- People of color account for only 17% of the total enrollment in 29 active protocols, while 54% of all PWAs are people of color, according to the CDC.
- The CDC has no transmission categories for lesbians or bisexual women with AIDS, making these women's lives invisible.
- Women are excluded from AIDS drug trials simply on the basis of sex, or are forced to be sterilized in order to receive drugs while men are not.
- When women and people of color can get into trials, they are often forced into placebo trials, historically often the only source of care for poor people.
- Women's deaths from pneumonia in many urban areas have increased as much as 100% while this and other potential AIDS connections are ignored.
- Drug protocols require potential participants to have a primary physician, effectively disqualifying women and people of color who can’t afford one.
- The FDA still supports the enrollment of babies, mostly children of color, in painful, dangerous and prolonged placebo trials. IVIG (intravenous immunoglobulin) placebo trials expose babies to opportunistic infections, hastening their deaths. The FDA will soon approve another placebo trial for children.
- As the AIDS crisis changes, cases of women infected with HIV are increasing; at the same time, women continue to die sooner after diagnosis than the average man with AIDS.
- HHS-funded AIDS research almost completely ignores any co-factors in AIDS other than HIV. Risk factors that especially affect poor people and people of color—such as the skyrocketing syphilis and tuberculosis epidemics in inner cities, nutritional aspects, and the full range of drug use (not just IV-drugs)—are barely studied.
- The FDA is responsible for every drug trial’s Institutional Review Board (IRB). These IRBs are usually made up of professionals, thus closing off access to groups who are working in affected communities, and self-help groups of women, people of color, and PWAs. People who are affected by AIDS have a right to be part of determining drug protocols and trial participants.
- Prisoners deserve access to treatment, and for full informed consent to experimental drugs. Of New York state prison deaths last year, 2 out of 3 were AIDS-related. The survival time for prisoners is only half as long as for those in the same demographic categories (like IV drug users) outside.

IT’S NOT JUST A VIRUS THAT’S KILLING US!!

FDA = INSTITUTIONALIZED RACISM & SEXISM IN THE AIDS CRISIS.

SILENCE = DEATH

ACT UP/NY WOMEN'S CAUCUS & MAJORITY ACTION COMMITTEE

We recognize that every AIDS death is an act of racist, sexist and homophobic violence!