

RADICALLY PINK

THE WORD
FROM
ACT
UP

Volume I Number 1

October 1993

We're Back

Yeah, yeah, we know. The ACT UP newsletter has been noticeably absent lately. Well, we finally got our act in gear, and we're back. Not only are we back, but we've had a little plastic surgery, and now the newsletter has a whole new look. We hope you like it. (If you don't like the look, keep your opinion to yourself. But if you've got anything to say about the content, then call us and say it. We want to hear you. Anyway, we've got a lot of things to share with you. Things we want you to ACT UP about. We're going to show you how to GET OFF YOUR ASS, GET EDUCATED and GET EMOTIONAL. So let's get going.

GET OFF YOUR ASS

DO IT!

Well, here we are -- twelve years into the epidemic (300,000 cases of AIDS, 200,000 deaths, and 50,000 new cases every year). And there is still no coordinated national plan to stop the spread of the virus; provide care for those infected; conduct basic scientific research into how the virus works; or improve the system of drug research development and approval. Why?

That's not a simple question to answer. But one important reason has been a lack of large-scale grassroots political effort by those infected, their families, friends, caregivers and advocates. Granted, many have devoted countless hours in many ways, but many more have not. Only a fraction of those affected by AIDS have been politically active and, therefore; the conservative right has dictated the agenda -- an agenda of hate and intolerance, of suffering and of death. How many letters have you written to your elected officials? How many calls have you made? Contact with your elected representatives by handwritten letter or personal phone call is one of the easiest and most important things any of us can do. Keep a pad and pencil and the enclosed phone/address card in a handy place, and contact your representatives and let them know how you feel on all issues that concern

you. Do it for those you loved and lost; do it for those you are losing; do it for yourself. Just do it, damn it!

THE GAY BAN

By now most of you are aware of the "don't ask, don't tell" compromise on the military ban on homosexuals. This compromise is unacceptable. It forces gay men and women in the military to hide in the closet -- to live a lie. However, it is a small step in the right direction.

While President Clinton clearly did not handle the issue well and did not fulfill his promise to lift the ban, he did at least deal with the issue. If it had not been for the staunch opposition by Democratic Senator Sam Nunn and other Democratic senators, we would have achieved much more. Sen. Nunn now joins the likes of Jesse Helms as one of the gay communities' most homophobic enemies. Though the issue will now be fought in court, we urge each of you to write a brief handwritten note to Sen.'s Boren, Nickles and Nunn expressing your disappointment.

This issue is still being challenged in court. We'll keep you advised.

IMMIGRATION BAN

Despite promises to do so during the campaign, the President has not done enough to end the ban on HIV+ persons who want to immigrate to this country. The ban continues. Senator Don Nickles and Congressman Ernest Istook were among the leaders in the fight to retain this discriminatory policy. We urge you to write or call Nickles and Istook and voice our opinion. Also write or call Clinton and urge him to take a lead.



GET OFF YOUR ASS cont.

SODOMY REFORM

Washington D.C. Mayor Sharon Pratt Kelly signed a sodomy reform bill last month after activists successfully guided the legislation through the city council. Twenty-three states and the District of Columbia currently have laws banning certain sexual acts between consenting adults.

Because D.C. is not a state, with only limited home rule, legislation enacted by the D.C. City Council is subject to a 60-day review period during which Congress can block implementation of the legislation.

Thanks to our own Ernest Istook, this bill was blocked. Continue to call and write Istook expressing your support for equal rights for all Americans, recognition of same-sex relationships and your opposition to government interference in our private lives in the form of sodomy laws.

JOCELYN ELDERS

Senator Don Nickles is leading the fight against Surgeon General nominee Jocelyn Elders. Nickles would prefer a nominee who will bow to the religious right, stick his/her head in the sand and ignore the realities of AIDS, teen pregnancy, etc....

We urge you to write Sen. Nickles and voice your support for Dr. Elders. By succeeding in delaying the vote for confirmation, Sen. Nickles has given conservatives a chance to organize, and we must counter their efforts. Please call Nickles and Boren **now**.

COMING EVENTS:

Mark Your Calendars and Come Join Us

World AIDS Day.....Wednesday, December 1, 1993.
Call 447-4209 for information on ACT UP actions.

National Coming Out Day.....Monday, October 11, 1993.
Join Queer Nation for Queer Day at the Mall,
Penn Square Mall, 6-9 p.m.
Call 447-4209 for more information.

ACT UP will resume **safer sex handouts at area High Schools** soon. Call 447-4209 if you would like to join us.

Legalize Living with Dignity

On September 7, 1993, a coalition of groups interested in a patient's right to herbal medicine held a major demonstration at the national headquarters of the Department of Health and Human Services. Following are excerpts from a letter written by Stephen Smith, the founder of Cannabis Buyers Club and Joel LeFever, Chair of Washington DC Metro Area NORML:

"Before its cancellation, HHS [Department of Health and Human Services] had a Compassionate Investigative New Drug (IND) program. This program provided government grown medical marijuana to those suffering from cancer, blinding glaucoma, and just before its cancellation - AIDS. This was not some haphazard give-away program; one had to go through numerous complicated steps in order to qualify.

But just as the AIDS community began to discover the existence of this program and the application forms began to pile up at the [HSS], the entire program was heartlessly terminated by former HHS Director James O. Mason.

Why? Because corporate interest could not make money from what Mother Nature provides for free. The idea of natural medications is unacceptable to those who profit from the suffering of others. People living with AIDS suffer from AZT side effects while taking ineffective Marinol (dronabinol), sold by the same industry that stands in the way of medical marijuana, so they can line their pockets with our blood money.

.. We have proof of President Clinton's prior interest and promise to restore the IND program:

Jackie Rickert of Mondovi, Wisconsin met candidate Bill Clinton on the Wisconsin campaign trail. She had the opportunity to explain her need of medical marijuana in her treatment for a rare degenerative condition similar to multiple sclerosis. She gave Mr. Clinton a packet of literature which further validated the medical efficacy of herbal THC. Mr. Clinton agreed to review the material and promised "to do everything in my power to help."

Jackie Rickert is still waiting. Unless we act, and act now, she will continue to wait--as will tens of thousands of PLWAs, cancer patients, glaucoma sufferers and many other sick people.

President Clinton knows, as we do, that marijuana, when used properly, provides relief for a host of minor ailments and that it stimulates the appetite. Remember the "munchies"?

What we are talking about here is maintaining or improving the quality of life for those suffering the most aggressive diseases ever to face humankind. Medical marijuana does work and it is already in use by hundreds of thousands of patients. But taking black market medicine makes them criminals subject to abusive treatment, jail terms and fines.

Join us as we work to pressure the president and HHS to legalize living with dignity while cures are sought."

For more information on how to help continue this fight, call 301-540-TOKE or 703-660-WEED or write DC Norml, P.O. Box 76605, Washington DC, 20013.

GET EMOTIONAL

What is AIDS?

Excerpts from the essay by Chris Brownlie, delivered by Phil Wilson, a person with AIDS, to a satellite meeting audience at the Berlin International AIDS Conference.

What is AIDS?

It is a whimper, and a scream.

It is being in your center, and being so far from your center that you don't know if you'll ever find your way back.

It is relentless. It is daunting, a great mountain which you must climb.

It is sweating, bleeding, puking, shitting in ways you never have before. It is pain you never imagined.

It is fear you never dreamed. It is grief you never guessed.

It is the frenzy of the medicine. It is too many visits to the outpatient clinic, the two days in the hospital for tests, the weeks for treatments.

It is the doctor's kindness, the nurse's caring, the phlebotomist's apology.

It is the manic need to make your mark, to leave worthwhile traces of yourself behind.

It is shattering denial every time the symptoms of another infection begin to mount.

It is the loneliness, like the whistle of a train passing in the dark night of your soul.

It is caring for your friends in a way you never have before. Intimate ways, horrible ways, ways that take more of your love than you knew you had.

It is being there when the coma comes, and it is begging in your heart for some little piece of mercy.

It is going to the church, or the park or the beach to say "Farewell and Godspeed, beloved one."

It is waking up wet, so wet, wetter than you were at

birth. It is having your skull split by its swollen lining.

It is anger: weird, quirky anger that knocks you off your pins and makes you doubt your own judgments.

It is being disoriented by the force of the great emotional wind which is constantly blowing within you.

It is the fighting back.

It is the building of places to care for the living and for the dying. It is courage, it is honor, it is integrity.

It is people joining forces in a time of great need.

It is hope, it is sharing the burden.



The devastation of AIDS was demonstrated when the Quilt came to OKC in 1992.

It is people caring for their own and finding love.

It is surviving and believing in the future even when we are hurting more than we have ever hurt before.

It is bearing the unbearable, enduring the unendurable, and hoping in the face of hopelessness.

It is the haunted look in your lover's eye when a new crisis begins.

It is mourning together. It is mourning alone. It is holding him in your arms and in your heart. It is crying because your heart is breaking over leaving him behind. It is the sweet pain of knowing that you are dying, and the overwhelming sadness for those who will kiss you into their dreams.

It is a wall. It is a howl. It is beyond our grasp.

It is awful. It is awesome. It is AIDS.

GET EDUCATED

Bill Promised An AIDS CZAR. He Gave Us The COURT JESTER

(Or Why We Can't Stand Kristine Gebbie)

*Gebbie supported lab-based names reporting for people with CD4 counts less than 200 so that Washington State could compile a list of persons with low T-cells. After compelling testimony by AIDS activists, the Board of Health adopted a compromise policy giving people the option of anonymous CD4 tests using a coded identifier to protect privacy.

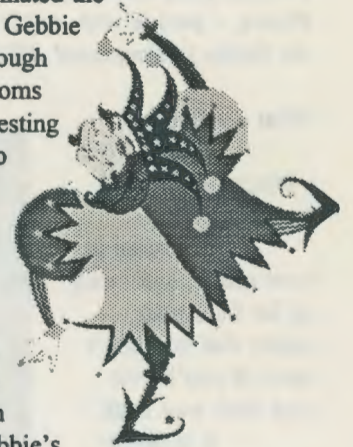
*Gebbie's Health Department wrote a policy for HIV Internment for persons thought to be 'casually irresponsible' in a draft submitted to the Governor's Advisory Council on HIV and AIDS in Washington State. The policy would create a process through the Washington Administrative Code to detain persons with HIV. After a public outcry led by ACT UP/Seattle, the Council rejected any discussion of HIV Internment, emphasizing that 'Intentional Infection' is a mental health issue, not an HIV issue.

*Gebbie was a principle architect of Oregon's Health Care Rationing Plan, called the Oregon Death Plan. Under this plan, diseases and afflictions are numbered from 1 to 800. Persons below a certain cutoff point receive only 'comfort care,' resulting in mandatory euthanasia for individuals living with low priority diseases. The plan pits disease against disease in competition for health care and has been opposed by groups like Project Inform, Physicians for Social Reform, and ACT UP's everywhere.

*Gebbie mistreated minority workers according to allegations in five complaints filed last year with the Washington Human Rights Commission. Pay discrepancies, dismissals, and a working atmosphere reminiscent of the "Old South" are described by minority workers in a recent article in the Daily Olympian.

*Gebbie lacked leadership when the Washington State legislature eliminated the Insurance Continuation program, Gebbie did nothing. Gebbie never took tough stands on needle exchange, condoms in schools, opposing mandatory testing or other controversial measures to fight AIDS.

*Gebbie left the Department of Health in Disarray, after a two-year tenure in Washington State. In an ongoing investigation by the Governor's office, Federal funding for the AIDS Prescription Drug Program disappeared in Gebbie's bureaucracy, winding up paying for urinalysis tests, not medications for People with AIDS.



In addition, the position itself is not cabinet level. The "AIDS Czar" reports to the Undersecretary of Health, who reports to the Secretary of Health, who reports to the President. There is also a lack of staff and funding. Write or call the President and tell him he can do better.

For more information contact:

ACT UP/Washington
1728 Wisconsin Avenue N.W. #A-139
Washington, D.C 20007 202-986-5512

ACT UP Is Listening Again

Yes, we know that lately when you have tried to call ACT UP, the machine has not been picking up the calls. But we now have a new answering machine, and we're ready to take your calls again. Sorry about the inconvenience, but please don't let that mechanical glitch discourage you. We like hearing from you, and calling the machine is also a good way to get a quick update on up-and-coming issues and events that are important to us all. So call 447-4209 and ACT UP!

Numbers to Live By:

Herland Sister Resources.....	2312 N.W. 39th.....	521-9696
Monday Night Clinic.....	2136 N.W. 39th.....	843-8378
Names Project.....	P.O. Box 12135 73127-2185.....	625-6277
Oasis Resource Center.....	2135 N.W. 39th.....	525-2437
OK Gay Political Caucus.....	P.O. Box 61186, 74136	
OK Gay Rodeo Association...P.O. Box 12485, 73157.....		943-0843
OKC Metro Men's Chorus.....		424-1753
Other Options.....	P.O. Box 36, Bethany, Ok 73008	
Pride Network, Inc....P.O. Box 12415, 73157-2415.....		340-3575
RAIN.....	924 N. Robinson, 73112.....	232-4372
Simply Equal Information Line.....		672-8852, Ex.1111
Teen Hotline.....	(Noon-Midnight).....	271-8336
Testing the Limits.....	2136 N.W. 39th.....	843-8378

GET EDUCATED cont.

State of the Antiviral Art

The following health information comes to us thanks to Project Inform 1993.

The State-Of-The-Art roundtable on the use of antivirals was held in late June in Washington D.C., where a diverse group of researchers, health providers, and community advocates gathered to review the bulk of data on AZT, ddI and ddC. Of special importance is the group's recommendation that treatment decisions be tailored to the individual, acknowledging that a 'cookbook' approach to managing HIV does not exist. Additionally, the group recognized that the decision to begin antiviral therapy should not be limited to approved indications for AZT, ddI and ddC, noting that a CD4+ count below 500 is not sole justification for initiating therapy, and the early use of combination antivirals is a reasonable treatment option. Monitoring health and laboratory work, involving the patient in treatment decisions and considering a number of factors including how someone feels about antiviral therapy were among the guidelines issued to physicians from this conference. At long last these guidelines incorporate flexibility and personalized therapy into standard of care. For more details on the specifics of this report, call the Project Inform Hotline.

Update On Opportunistic Infections

While not much new information was presented in Berlin, there have been many new developments in research into opportunistic infections over the past six months. New and better therapies for treating HIV and HIV-related conditions are on the horizon. The following is a highlight of recent advancements in this area of HIV research.

Mycobacterium Avium Complex, MAC - sometimes called MAI, is the most common form of bacterial infections in people with HIV. The FDA recently recommend Clarithromycin (Biaxin) for approval for treating MAC. It is to be used in combination with at least one other drug. A large study comparing three doses of clarithromycin for treating MAC found the highest dose, 2000 mg. twice a day, to be too toxic. The other two doses, 500 and 1000 mg. twice a day, were equally effective, demonstrating marked decreases in symptoms. Drug resistance is a problem when clarithromycin is taken alone for treating MAC.

Rifabutin (Mycobutin) was approved for MAC prevention late last year. This drug will add to our arsenal in preventing OIs and additionally raises awareness about another mycobacteria infection, tuberculosis, as a test for TB is required prior to initiating prophylaxis with rifabutin.

Cytomegalovirus, CMV - new developments for CMV include intravitreal implants, a pellet containing ganciclovir that is slowly released into the eye. The pellet is surgically implanted into the eye and lasts for 4-8 months. There is a clinical trial ongoing comparing a 4-month device to an 8-month device. Previous studies showed the 4-month device to be effective in controlling retinitis. Advantages of the device is that it eliminates the need for central catheters and daily infusions, as well as toxicities associated with either ganciclovir or foscarnet. The major disadvantage is that it provides only local therapy (the retina) and will not prevent CMV from developing elsewhere, although researchers report this to be a problem in less than 15% of patients.

HPMPC, a new drug under study is very potent against CMV in test tubes. Most of the studies done thus far are with an intravenous formulation of HPMPC, but subcutaneous and oral formulations are also being developed. The appeal of this drug is that it stays in cells for a very long time and it is possible that infusions will only be needed once a week, every two weeks, or possibly once every three weeks. Thus far studies reveal this drug to be very toxic, with the most serious toxicity being damage to the kidneys.

Oral toscarnet has just entered phase I trials in England. Clinical trials should begin in the United States upon completion of the British study. If found to be effective, this drug could prove useful in preventing CMV and also recurrences of CMV.

Data from two trials comparing IV to oral ganciclovir to prevent the recurrence of CMV have yielded disappointing results for the oral drug. Newer data, at a higher dose, are more encouraging, however. There are plans for a parallel track program to begin by the end of the year for the oral drug, at the higher dose, and will be open to people who have developed bacterial infections as a result of IV catheters. Two trials for preventing CMV are ongoing.

Cryptosporidiosis is a protozoan infection that causes severe diarrhea, abdominal pains, and weight loss. There are no approved treatments for this infection. One trial looking at letrozol for the treatment of cryptosporidiosis found that although the drug eradicated oocysts (eggs from this parasite), the drug did not alleviate symptoms of the disease.

Microsporidiosis, another protozoan infection, causes the same symptoms as cryptosporidiosis. One promising drug to treat this infection, albendazole, is available on a compassionate use program. Physicians should call 800-366-8900.

Pneumocystis Carinii Pneumonia, PCP - Atovaquone (Mepron), formerly known as BW566c80, was approved for treating PCP late last year for people who are intolerant of Bactrim/Septra. A new liquid formulation of atovaquone has just entered clinical trials. The new formulation may also prove useful in treating toxoplasmosis.

Trimetrexate is now also available through an expanded access program for people who have failed Bactrim/Septra and also IV pentamidine. Physicians should call 800-537-9978.

ACT UP has accumulated a significant amount of treatment information. If you would like information on Antivirals or treatments for OI's, please submit a request in writing to ACT UP, P.O. Box 60886, OKC, OK 73146. Be as specific as possible, and we will make and mail copies of pertinent items.



Oklahoma City ACT UP and Queer Nation had Dale Smithson, Tina Steeves and Helen Miller as three of their representatives at the 1993 March on Washington. As you can see, they had a great time!

ACT UP/OKC
P.O. BOX 60886
OKC, OK 73146