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The Murder of Our People - Genocide of Gay Men in America Paul Benetberg - National Mobilization Against AIDS

President Reagan - "We should send him (Khadaphy) to San Francisco"
Secretary of State - "We could give him AIDS"
Cabinet of the United States - "Laughter"

If across the nation Irish Catholics were being murdered by a sinister group the public would no doubt demand that government act to protect them. If the murders doubled annually but the governments response remained slow and ineffective what would public opinion conclude? Perhaps in the first year of murders they would believe the authorities to be incompetent and insensitive. In later years, as the murders continued, perhaps negligent or derelict in duty. But if the government took little action even when tens of thousands of Irish Catholics were dying annually after years of unending murders would not most people conclude that the government wanted Irish Catholics murdered or at least was prepared to tolerate their extermination? Of course they would because the primary responsibility of government is to protect its citizens. When a government tolerates the death of a group of its citizen which it can prevent it is as malicious as if a policeman witnessed a lynching and did nothing. Thus at some point in the AIDS epidemic the Federal government's inaction has ceased to be incompetence and become complicity.

MOBILIZATION AGAINST AIDS



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FIGHTING FOR AN AIDS STRATEGY OF HOPE

by Paul Boneberg
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" 263,000 of the projected 365,000 AIDS patients are predicted to die by the end of 1992."

U.S. Centers for Disease Control

The above statement is wrong and exemplifies the error in this nation's AIDS strategy. The government policymakers assume that we must fail in efforts to stop AIDS before it kills hundreds of thousands, if not millions, of Americans. The government's plan describes this assumed failure year by year, projecting increased deaths every year with 219,000 Americans dead by 1991 alone. Indeed, the unspoken anticipation is that virtually all of the 1.5 million Americans infected in the "first wave" of this epidemic (infected before 1982) will soon die.

Consequences of the Existing AIDS Strategy of Doom

1. Government funding for AIDS research, particularly for treatment, continues to be woefully inadequate. For example, Dr. Anthony Fauci, head of the AIDS programs for the National Institutes of Health, has been denied two-thirds of the AIDS research positions he requested in both 1989 and 1990 because neither the Bush administration nor the Congress, nor the American people, believe the NIH can beat AIDS.

2. AIDS researchers in government, universities and private corporations move slowly in publishing data, receiving drug patents and complying with the infinite requirements of marketing new drugs. After all, who wants to jeopardize corporate profits and the Nobel prize by hurrying research when it won't come in time to save most people anyway?

3. The medical bureaucracy (the Food and Drug Administration in particular) has not created a mechanism to quickly get promised drugs to people fighting HIV infection. For example, in 1988 17,000 people died of pneumocystis pneumonia despite the existence of a drug which prevents such cases 90% of the time. Why should they create such a mechanism when everyone assumes these people can't be saved anyway?

4. HIV-infected people refuse to participate in research studies, or if they do so, they covertly take "underground" AIDS treatments simultaneously, thus ruining the research data. After all, why participate in research that offers no hope for yourself, your friends, or your community?

5. Many insurance companies and Medicaid refuse to pay for drugs and treatments which clearly extend the lives of HIV-infected people. Thus the wealthy can avoid pneumonia or blindness, while the middle class and the poor cannot; the health insurers assume their death despite the availability of promising drugs.

6. People at risk of being infected do not seek testing or treatment because they wrongly believe nothing can be done to help them medically. In San Francisco, for example, two-thirds of the gay men have not been tested, and of those who have, few are in the continuing follow-up care which might well save their lives.

7. Virtually all Community-based AIDS organizations--the backbone of the AIDS struggle -- remain officially neutral about the HIV antibody test, despite its obvious medical benefit. Lack of access to follow-up care and civil rights concerns are their valid concerns, but it means that HIV-infected people who turn to them for leadership do not hear a strong counter to the government assumption of their deaths.

Thus the culmulative impact of the government's AIDS strategy of doom is to guarantee our failure in the war against AIDS. Instead of a unified national effort by researchers and patients, the government and the private sector to save the lives of so many Americans, each group works in a slow and cumbersome fashion on a small part of the AIDS challenge.

The Medical Facts Have Changed

In December 1988, Mobilization Against AIDS became the first AIDS organization in the nation to change its position on the HIV antibody test (we now urge people to take it). As California's oldest AIDS advocacy group, we are keenly aware of the dangers of civil rights abuse, but the medical facts have changed, and people must be so informed.

The essence of this change can be summarized in one word -- hope. On this hope government policy on AIDS should now be based. We contend that HIV infection is now a life-threatening disease, but it may or may not be a fatal disease, depending on the speed with which research proceeds and people are given access to promising AIDS drugs. We base this on the following:

1. AZT and other drugs have already doubled the life expectancy of the most vulnerable group of people who are already sick with AIDS. "Pneumocystis pneumonia increasingly appears to many of us to be a preventable opportunistic infection, with agents of probable activity including Septra as well as aerosol pentamidine." (Dr. Paul Volberding, in letter to Mobilization)

2. New drugs can significantly slow the natural course of the disease. Aerosol pentamidine, for example, prevents pneumocystis pneumonia in 90% of infected people. "With regard to opportunities for therapeutic intervention, considerable optimism exists for the discovery and development of new and improved treatment of HIV infection and AIDS....several drugs have proven effective or hold promise for the treatment of opportunistic infections associated with the disease, such as pentamidine for pneumocystis pneumonia and DHPG for cytomegalovirus." (Dr. Anthony Fauci, in letter to Mobilization)

3. Scientists are extremely hopeful that other drugs-- particularly those designed to be administered to people who are infected but still healthy -- will soon be developed. "In addition to significant advances in the prevention and treatment of opportunistic diseases, we will quite certainly see emerge, within the next five years, effective regimens of treatment against HIV-infection itself." (Dr. Mathilde Krim, in letter to Mobilization)

4. Nearly 100 new AIDS drugs are being currently tested, some of which -- such as GLQ-223, DDI, and DDC -- show extreme promise. "There are many promising drugs currently being tested and, therefore, the availability of new effective treatments is certainly possible in the near future." (Dr. Mervyn Silverman, in letter to Mobilization)

Every scientist we spoke to was hopeful, and many felt the government's plan of projected deaths was already outdated and incorrect. Dr. Anthony Fauci, head of the AIDS programs at the National Institutes of Health, wrote us that "there is reason to believe that soon we may be able to reverse, or at least arrest, those projected trends (of AIDS deaths)....It is entirely possible that by treating HIV infected individuals earlier, before they are seriously ill, the entire course of the disease process can be significantly altered." Further, every scientist and physician supported the idea that testing and monitoring the immune system of an infected person was to that person's medical benefit.

We agree. People who know they are infected, monitor their immune system, and take preventive drugs when required (such as aerosol pentamidine) have a better chance of survival than those who do nothing. It is entirely conceivable that those who survive these next few years may survive much longer, living

under constant medical care much as do adult diabetics. This is not to say that they would have a normal life span - that would depend on research - but it would mean that they would not quickly die.

Indeed, human trials have begun at the University of California on the first drug that might be a cure - GLQ223 - which kills infected cells in the test tube. Whether it works we do not know. We do know that if it does work, there would be no pre-existing system to quickly get it in the hands of HIV-infected people. It will have to pass through the infinite steps that still exist in a health bureaucracy that believes that such a drug is impossible and that all HIV-infected people will soon die.

Creation of A Strategy of Hope

It behooves all AIDS organizations, policy makers and scientists to speak out against the existing strategy of death and help define a Strategy of Hope. We see that strategy as a unified effort by AIDS activists, scientists, the medical profession, communities at risk and the government to save the lives of all infected people. Some components of this strategy would be:

1. Passage of strong federal legislation which guarantees that no American will be discriminated against because of HIV infection. Without such a law, many people will not seek treatment or be tested.
2. A fully funded federal "Manhattan Project" style reasearch effort for treatment methods. This effort must be highly coordinated with drug and pharmaceutical companies.
3. A system which allowed physicians to prescribe experimental AIDS drugs while they are being tested; i.e. early in phase 2 trials.
4. A national educational system for physicians to guarantee that they are informed of the latest HIV treatment information.
5. A national educational campaign targeted to people at risk of HIV infection, urging them to be tested and, if infected, to seek treatment. This is a change from existing programs which are neutral about the testing and do not emphasize follow-up treatment.
6. Creation of coordinated health delivery systems that guarantee that no infected person would be denied treatment due to the inability to pay.

7. Creation of model HIV treatment centers which would establish the best standard care guidelines for the HIV infected.

We must act quickly to implement our Strategy of Hope, for every passing hour brings more deaths and more AIDS diagnoses. 95% of Americans infected with HIV are still alive: most are still healthy. But research shows that without treatment, nearly all will soon become ill, for they have been infected for several years already.

The first step is for AIDS activists to emphasize early treatment and the other aspects of the Strategy of Hope. Second, AIDS researchers and physicians need to lend their voices to document and articulate the treatments which will save lives. Finally, Congress and the President must act to fund and coordinate a positive, pro-active AIDS strategy.

I believe the American people would strongly support us. For one thing, our strategy not only saves lives -- it would save money. But more important, Americans like to win their wars, and once they realize the war on AIDS can be won, that is what they will demand.

Anything else is not merely unconscionable -- it is contrary to the American spirit. The creation of an AIDS Strategy of Hope is within our power if we take action now.

" I say to all HIV-infected people that they should not think in terms of dying of their HIV-infection, but of fighting it and controlling it, in the interim, with all medical, attitudinal and, yes, political means available to them."

Dr. Mathilde Krim,
Founding Co-Chair, AmFAR

MOBILIZATION AGAINST AIDS

BRAINSTORMING ON POSSIBLE AIDS ACTIONS

Paul Boneberg
Executive Director
Mobilization Against AIDS

To best utilize our limited resources in 1988, I suggest we in California undertake a series of actions, always focusing as much as possible on the "research and treatment" issue.

1. Conduct immediately a survey of public opinion on AIDS issues to ascertain more clearly our options. Cost: \$40,000.
2. Force AIDS into the national debate including forcing all presidential candidates to address the issue in depth.

In the long run this is our greatest challenge. One of these candidates will become the most important person on AIDS in the world in 13 months.

One or more state and national groups should begin a "candidate watch" to insure that where a presidential candidate appears we raise the issue of AIDS - particularly treatment. Simultaneously, more mainstream groups should be educating the candidates and their staff. The goals of this action should be a) to personally motivate the candidates on AIDS; b) to force the candidates to issue detailed position papers on AIDS; c) to force the candidates to appoint AIDS advisors to their campaigns who will later serve as their transition team experts after the election; and d) to make AIDS, particularly AIDS treatment, a viable issue in the 1988 political debate. Candidates should do press events around AIDS, independently raise the issue during debates and address AIDS in the nomination acceptance speech.

In addition to being present with pickets, questions, etc. when they appear, we should consider the following actions to force them to take action:

- a. Saturate Iowa and New Hampshire voters with questions and facts on AIDS and thereby force the issue into the early primaries where the candidates are most accessible.
- b. Construct presidential AIDS forums and finesse the candidate into appearing.
- c. Organize dramatic AIDS actions at both national conventions.

I believe a large march is not feasible and suggest instead mass civil disobedience coupled with a petition drive. We could demand to present petitions to each candidate personally and if they refuse be arrested trying to "petition" them.

d. The most visible action we could take on AIDS to force the next president to address the issue would be a large march and civil disobedience on Inauguration Day, January 20, 1989.

All the above actions are within ability of existing groups to undertake either alone or jointly. Estimated cost: \$100,000 to \$1,000,000.

3. Lobby groups should make pro-active AIDS legislation-focusing on treatment, their number one priority, even if this means losing some other issues.

I believe that the legislative example for us to follow is the Filante - Van deKamp treatment bill in California last year. This bill's passage demonstrates the bold legislation on treatment or research presented in a bi-partisan manner can become law. All state and federal lobby groups should identify and lobby for equivalent constructive legislation as their first priority.

The Doolittle and Helms attacks will continue and can only be stopped by putting pressure on liberal democrats to kill the bills or offer alternative legislation. Alternative legislation is the only way of stopping the "increased penalty bills" and the easing of test confidentiality which the medical community desires.

Existing resources and structure are sufficient to undertake these efforts if the groups will work closely together.

4. Opposing LaRouche - Dannemeyer initiatives with lean counter campaigns.

We cannot take the chance that we can defeat these initiatives without credible counter campaigns. Assuming an extreme shortage of both volunteers and funds, we must recruit savvy campaign managers who can "do more with less." We particularly need people who can maximize our media exposure at very low cost. We should recruit a board and 2 to 4 campaign staff people by early January. Estimate campaign cost: \$500,000.

5. Place our own pro-active AIDS initiatives - focusing on "research and treatment" on the November ballot.

The goals of our own initiative on the ballot are to secure a

breakthrough on treatment efforts, to shift the public debate from "civil rights" to treatment, and to motivate our community and give them hope. Even if we loose the initiatives themselves but significantly change public opinion on treatment issues, we have a net gain.

We must move extraordinarily quickly to put our own initiatives on the November 1988 ballot. I suggest we choose 4 or 5 initiative proposals and circulate them simultaneously. We should also pressure the legislature to put them on the ballot to save us the effort of collecting signatures. Campaigns can be run independently or jointly once we know what's on the ballot. Cost: 1 to 2 million dollars for all.

Possible Initiatives

a. Direct the Governor and legislators to create an Emergency AIDS Task Force, consisting of AIDS experts. Place at these experts disposal 50% of the States' Emergency Reserve over the next 2 years.

b. Direct the Governor to declare California a natural disaster area in order to secure immediate federal funding for AIDS.

c. Place a \$450 million bond issue on the ballot to pay for 3 HIV treatment facilities for 3 years.

d. Place 1/2 of sales tax (or a gasoline, tobacco, liquor, tax, etc.) on the ballot with funds targeted at AIDS.

e. A directed tax credit initiative is being proposed by Grey Davis, Bruce Decker and others. We should support this initiative.

6. Other thoughts.

o Our PACs should run well financed campaigns against Senator Doolittle and Dannemeyer. Such campaigns could be net fund raisers for the PACs if well packaged for our community. Both candidates are vulnerable for being against increasing AIDS funding.

o We should brainstorm on how to punish Jess Helms. Possible suggestions include boycotting tobacco companies based in North Carolina or increasing taxes on tobacco.

o Lesbian and gay Democrats and Republicans should lead the punishment of elected officials in their party when they vote wrong.

c The Annual American Medical Association meeting in Chicago in May is an ideal place for future civil disobedience.

c Our educational AIDS areas should direct major resources to "supportive" advertisements in the mainstream election media.

c People with AIDS and HIV infection should be recruited to be delegates at both conventions where they should be visible.

c People with AIDS and HIV infection should be recruited to run as protest candidates against unbeatable legislators who vote wrong (ie. Dannemeyer - Roberti - Brown).

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MOBILIZATION AGAINST AIDS

SAVING THE LIVES OF ONE MILLION GAY MEN

Going on the Offensive on AIDS

Paul Boneberg
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Treatment. I believe the most important challenge to AIDS activists in 1988 is increase research efforts to find a treatment for HIV infected people.

We are a people under siege. A million or more gay men will die if the siege is not broken. We cannot continue in a defensive posture "circling the wagons" ever tighter in the face of growing civil rights assaults. Even if we defeat the Helms, Doolittle attacks, our people will still die from the AIDS virus. We must take the offensive to obtain a treatment and then a prevention and cure for AIDS. This will entail neglecting reactive political organizing, particularly around civil rights, to become more pro-active on AIDS treatment. This is a dangerous decision for we could suffer enormous civil rights losses and not significantly improve the life expectancy of HIV infected people. Yet, soon these million men will begin to die at a rate approaching 10% a year and, therefore, I believe we have no choice but to seize the offensive. For our efforts to succeed, we must be bold.

As the Executive Director of Mobilization Against AIDS, I have access to a number of the nations leading "AIDS experts"-medical and political, both within and without government. I have spoken to numerous 'experts' during the last months of 1987 to see if there is a consensus on the various problems we face in the next few years.

Here are the conclusions I have drawn from those meetings:

1. Between 1 and 1.5 million people are infected in the U.S., approximately of which 2/3 are gay men. Most of these people were infected over 5 years ago.
2. The spread of the infection among gay men has virtually stopped. New infections appear to be below 1% per year and declining.
3. The next wave of infection will occur among IV drug users and their sex partners.

4. Most of those already infected will either suffer disabling illness or die at a rate of 10% a year with 80-90% dying or becoming severely ill within 10 years.

5. The development of an effective treatment (ie. as effective as insulin is to diabetes) within the next 10 years is possible but by no means certain or even probable.

6. The development of an AIDS vaccine or a cure (ie. killing the virus) is years away and may not occur for decades. Both are beyond the capacity of current medical science.

7. The health care costs of treating the future AIDS patients will be high but could be borne by the medical system if there was the political will to do so.

8. Civil rights battles around AIDS will accelerate because compromising the rights of HIV infected people will be the only immediate dramatic action government can offer a frightened populace. Although, civil rights assaults will undermine the society's ability to fight AIDS, few elected officials will have the strength to oppose such assaults. (Example - Senate vote of Helms' amendments)

9. The medical community will join in calling for a weakening of many AIDS civil rights safeguards particularly written consent for HIV testing and the sharing of test results among health workers. (Example - CMA opposition to recent AIDS civil rights legislation, ie. Agnos A.B. 87)

10. The media will accelerate its phoney "civil rights as health policy" coverage to the detriment of HIV infected people's civil rights. A vast amount of media coverage will be given to so called "recalcitrant people with AIDS" (ie. Patient Zero).

11. Among politicians, our enemies will attack us but our friends will avoid the AIDS issue because of its gay connection (eg. Doolittle, Helms debate).

Juxtaposed with these problems are six positive facts:

12. The lesbian and gay community has been extraordinary by any historical analysis in its efforts to stop AIDS. Further, we have far greater resources and determination than has so far been utilized. I believe fund raising and volunteers can be increased at least 100%.

13. The United States is the greatest scientific and economic power in the world has ever known. If the full weight of its resources are directed to stop AIDS, we have a good chance to

quickly develop an effective treatment for HIV infection.

14. The State of California alone as one of the world's leading economic and scientific entity could itself shorten the epidemic by maximum utilization of its resources.

15. Polls indicate that most Americans do not support overt discrimination against HIV infected people. Further, many Americans believe that AIDS is a problem of great importance which the government has failed to adequately address.

16. The Presidential election of 1988, with its attendant party conventions, gives us a spectacular opportunity to influence popular opinion.

17. In 14 months someone other than Ronald Reagan will be President.

In California and the U.S. these facts translate into a series of political crises. These include the following:

- o There are no viable legislative efforts which accelerate research enough to give us the medical breakthrough needed to save those now infected.

- o The Doolittle AIDS Legislative Package will be back with increased momentum in January.

- o Lyndon LaRouche has placed his AIDS quarantine initiative back on the ballot in June.

- o Dannemeyer, Doolittle, Gann and others will place AIDS civil rights assaults on the November ballot.

- o Jesse Helms will be pushing increasingly radical AIDS amendments through Congress.

- o None of the candidates for president has included AIDS a major theme in their campaigns; none have an adequate position on AIDS. AIDS has not been raised in any of the political debates.

Recommendations -- I suggest the following actions as effective utilization of the limited resources we have at our disposal in 1988. These are expanded upon in a separate document titled "Brainstorming on Possible AIDS Actions:"

1. Conduct immediately a survey of public opinion on a wide variety of AIDS issues to determine our best course of action.

2. Force AIDS into the 1988 national debate, including forcing

all presidential candidates to address the issue in depth. This should involve a national petition drive, civil disobedience at both national conventions, a large march and civil disobedience at the inauguration, and countless local demonstrations.

3. Lobby groups should make pro-active AIDS legislation, focussing on treatment, their number one priority, even if this means losing some other issues.

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all presidential candidates to address the issue in depth. This should involve a national petition drive, civil disobedience at both national conventions, a large march and civil disobedience at the inauguration, and countless local demonstrations.

3. Lobby groups should make pro-active AIDS legislation, focussing on treatment, their number one priority, even if this means losing some other issues.

4. Oppose the LaRouche, Dannemeyer initiatives with lean counter campaigns of our own.

5. Place our own pro-active AIDS initiatives, focussing on "research and treatment," on California's November ballot.

MOBILIZATION AGAINST AIDS



1540 Market Street, Suite 60
San Francisco, CA 94102
(415) 863-4676

Mobilization In-Depth Briefing for Select Supporters
February 2, 1989
50 Ashbury Terrace, San Francisco
6PM to 8PM Thursday

SPEAKING: Paul Boneberg, Mobilization Executive Director
Dr. Don Francis, Centers for Disease Control
Brandy Moore, Aide to Speaker Willie Brown

AGENDA:

1988

Dukakis - A quick report from our meetings with Michael and Kitty Dukakis and their top staff during the campaign addressing the following questions: Why couldn't Dukakis generate enthusiasm from AIDS activists? Was Kitty Dukakis really a significant player on AIDS? Why did Dukakis take so long to come out against Proposition 102? Why did Dukakis say that he and Bush basically agreed on AIDS in the first debate?

Proposition 102 - An overview from the first organizational meeting to the invisible victory party, discussing why the AIDS leadership nearly allowed 102 to pass, why we almost lost the campaign and the reasons why we eventually won, and why there was no significant opposition to Proposition 96.

1989

Launching a Strategy of Hope - An examination of the following topics: Why the projections of death from AIDS are wrong; Why Mobilization has become the only AIDS lobby group in the nation to make early treatment its number one priority; A report from our meetings with leading AIDS researchers including Dr. Anthony Fauci, head of the National Institutes for Health's AIDS programs and President Bush's "hero".

Current Issues - An analysis of the following subjects: Is there hope for those infected with the HIV virus? Is current funding for research adequate? Is AZT the answer for people infected with AIDS? The problem of creating a consensus around aggressively urging people to get into early treatment; How to pay for 1.5 million people to get treatment for HIV infection; Legislative solutions in 1989; The issue of positive AIDS ballot initiatives in 1989 and 1990.

MOBILIZATION AGAINST AIDS



1540 Market Street, Suite 60
San Francisco, CA 94102
(415) 863-4676

Wednesday, January 25, 1989

To: Mobilization Against AIDS Supporters

From: Paul Boneberg, Executive Director

Re: Agenda for In-depth Briefing

In the last few days we have received phone calls from some of you invited to the in-depth briefing for select members inquiring about the content and format of the meeting. The briefing is a candid off-the-record discussion by Mobilization staff and a few AIDS experts as to what really happened in the politics of AIDS in 1988 and what needs to be done in 1989. Attendance at this briefing is limited to between 15 and 40 people by invitation only. It is intended to give those who have supported Mobilization Against AIDS by significantly contributing either time or money a behind-the-headlines look at how an AIDS lobby group analyzes and reacts to political, governmental and scientific developments in AIDS.

Finally, this is not a fundraising event. There is no charge; there will be no "pitch". The routine business of keeping this organization alive will be discussed in countless letters and maybe a few phone calls by our Development staff in the months ahead.

The briefing will be between 60 and 90 minutes and there will be ample time for questions. If this interests you, please call Drew Siegel to confirm at 863-4676.

MOBILIZATION AGAINST AIDS



1540 MARKET ST., SUITE 60
SAN FRANCISCO, CA 94102
Telephone (415) 863-4676

Mobilization Against AIDS is pleased to invite you to the first in a series of AIDS Policy Briefing Sessions. The event will be held on **Thursday, February 2, 1989, at the home of Tom Lloyd at 50 Ashbury Terrace from 6:00 to 8:00 pm.** Directions are attached. Please RSVP to Allan at 863-4676 as soon as possible.

Because you are all sponsors of Mobilization, there will be no charge for the Briefing Sessions. It's our opportunity to give something back to you. We will be providing you with a package of information about Mobilization and its plans for the coming year. (Mobilization is a nonprofit agency, however, meaning freely given contributions would be helpful. Guests who might be interested in supporting Mobilization are welcome too.)

Thank you very much for your assistance. Together we have accomplished much but we must use that progress to achieve even more. Join us on February 2 to discuss what lies ahead.

Paul Boneberg,
Executive Director

AIDS Policy Briefing Session

Each AIDS Policy Briefing Session -- we plan three in 1989 -- will serve to keep interested and active persons like yourself informed about AIDS policies on the local, state and national levels. Mobilization has worked for years to build relationships with health care providers and policy makers, with politicians and administrators and with the leaders and volunteers of many of the nation's AIDS service and care providers.

The Briefing Sessions will share our results and our expectations for the future with you -- the individuals who have supported Mobilization's many past efforts.

The coming year holds difficult challenges. Projections of death still loom even as hope lingers. Mobilization will be pushing for a recognition of the need for individual testing and early treatment intervention as part of that challenge at the same time that we acknowledge the dangers of unprotected AIDS antibody test results.

The reason why is critical to understanding what medical, health and legislative leaders are saying about AIDS and the successes and failures expected in the future. Come let us know what you think.

List of invitees for Tom Lloyd AIDS Briefing Session 89

AIDS Policy Briefing Session

Tom Brougham	Dorothy Spact Guerrero
Emily Rosenberg	Mary Shipman 751-8577
Donna Schwarz	Dave Semrow Bronte St
Laurie McBride	Ray Sabie 824-1669
Ken McPherson	Tim Royes 776-1446
Linda Keeton N/A	John Petrie 441-1264
Nancy Kirk 431-9245	A. Niscon 776-5228
2y Max Kirkeberg 782-6022	Mary Mejia 586-2402
Jarrold Kunz N/A	N Maurice Loomis 771-2143
Cara Marks N/A	N Duane Lindoff 566-3830
Kathleen Mason Filbert St	David ^{Lysle} Leatie 864-6406
Aiden Mcaleenan 474-3226	Rodger Lamm Doyle
George McGuire 861-2343	Tom Koube 775-3777
Kenneth Mills Hardley St	Karen Q Johnston
Maybe Robert Rogers 552-6743	Dorine Hurst 821-2287
N Donald Disler 392-2800	Michael Hollars 646-7129
Robert Douglas Demoset St	Dan Hampshire 641-1740
Raymond Escobar 863-5423	Dr. Jan Gerritsen 945-6564
Eva Fredricks, Images of Success 400 Market St, Oak	Y Chuck Forester 931-1514
R. J. Hacking 965-3804	Ginny Foat 320 Clement
Robt. Annetone 861-1274	N Bill Essex 863-8867
David Bakam 547-4700	Dr Jeff Ghe 285-5988
William Bartley 547-4700	Rbt Cohen 935-1953
Sue Bershad Lee St	Christopher Colenga 27th Ave
Richard Bring Waller St	H deWilt California St
James Campbell Edgewood Ave	Herb Donaldson 10th St
Dolores Caruthers Lincoln Village Circle, Lakeside	
Kevin Cavanagh Walker St	
Linda Christensen Russell St	
Jim Cimino 845-0924	
A. Lindley Cotton 821-2061	
y Natalie delaRoziera (468) 476-1475	
Brian Friedman 558-9434	
Arlynn Frisen Carmelite St	
Kristi Habedanck 277-5637	
John Hoffman 14th St	
Charles Holmes Continent America 1295 Folson St	
James Hormel 546-7635	
Berry Jeffrey Haney 861-3338	
Gregory P. Howe 863-6284	
Dennis P. Nx Greenview Dr. Daly City	
Gregory Omi 22nd St	
William Owen Valencia St	
Elizabeth Rish 863-7103	
Dr. Elliot River 31st Ave	
Laura Sarden Chestnut St	
Natalie Silverman Saroni Drive, Oak.	
Donna Strand Salem Way Fremont	
Keith Vacha Hayes St	
Paul Anderson 821-1093	
Vicki Bier Paige Lane Costa Mesa	

11 more



January 18, 1989

Mobilization Against AIDS
1540 Market, #60
San Francisco, CA 94102
Attn: Allen

Dear Allen,

Here's the list of names that I promised you:

Mr. Don Angus
N Mr. Jerry Berg
N Mr. Mark Cloutier
Mr. Todd Dickinson
Mr. Jeffrey Leiphart
Mr. Rob Eichberg
Y Mr. Chuck Forester
Mr. Jeffrey Fraenkel
Mr. David Fox
Mr. Dewey Green
Mr. John Hall
Bob. Not Mr. Jim Hormel
Mr. Tom Nolan
Mr. Bob Sass
Mr. Alvin Schaaf

Please give me a call if you have any questions.

Sincerely,

Mark Leno



CONGRESSMAN HENRY A. WAXMAN NEWS

2418 RAYBURN HOUSE OFFICE BUILDING
8425 WEST 3rd STREET

WASHINGTON, D.C. 20515
LOS ANGELES, CALIF. 90048

202-225-3976
213-651-1040

For Immediate Release
June 3, 1991

For further information, contact:
Tim Westmoreland 202-225-4952

Hearing On Ten Years of AIDS: The Past and Present of the Epidemic

Washington, DC—The Subcommittee on Health and the Environment will hold a hearing on the past and future of the AIDS epidemic. The hearing will be held on Thursday, June 6, at 9:30 a.m. in Room 2123 Rayburn.

June 5 is the tenth anniversary of the first published report of cases of AIDS. That report, which appeared in the Morbidity and Mortality Weekly Report (published by the Centers for Disease Control (CDC)), was authored by Dr. Michael Gottlieb of Los Angeles. Since that time, the CDC has reported more than 100,000 American deaths and estimated that one million Americans are infected with the virus that is thought to cause AIDS.

The Subcommittee will receive testimony from a range of experts on AIDS who will discuss epidemiology, research, and treatment of AIDS.

Witnesses will include:

Dr. Michael Gottlieb;

Dr. Ted Cooper, Chairman of the Committee of AIDS Activities of the Institute of Medicine of the National Academy of Sciences;

Dr. Lonnie Bristow, on behalf of the American Medical Association;

Dr. Robert Redfield, Walter Reed Army Medical Center;

Mr. Dan Bross, on behalf of the AIDS Action Council; and

Mr. Paul Boneberg of the Mobilization Against AIDS.

Congressman Jim McDermott (D-Wash) will also testify about AIDS in developing nations.



NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
May 9, 1991

Contact: Thomas Brandt
202-254-5125

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June E. Osborn, M.D.

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Eunice Diaz, M.S., M.P.H.

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Belinda Mason

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Hon. J. Roy Rowland, M.D.

Hon. Louis W. Sullivan, M.D.

EXECUTIVE DIRECTOR

Maureen Byrnes

San Francisco Hearings to Focus on Sexuality and Public Policy; also Asian, Asian Americans and Pacific Islanders

The National Commission on AIDS will hold hearings in San Francisco May 16 and 17 where presenters the first day will focus on sexuality, HIV disease and government policy. The second day is devoted to the impact of the HIV epidemic on Asian, Asian American and Pacific Island communities.

June Osborn, M.D., Chairman of the National Commission on AIDS, said, "Our national diversity, including differences of ethnicity and sexual orientation, is critical to how people in America respond to the challenges of AIDS and HIV infection.

"In the first day of hearings we will focus on society's concepts of sexuality, especially issues around gay, lesbian and bisexual orientation, and how these concepts relate to the HIV epidemic and government policy," she said.

"On the second day, the hearings will extend our awareness of racial/ethnic issues as we hear from

-more-

representatives of the Asian, Asian American and Pacific Island communities," she added. Dr. Osborn is also Dean of the School of Public Health at the University of Michigan at Ann Arbor.

Larry Kessler, a member of the National Commission, said, "Of great interest to the Commissioners is deepening our understanding of some of the progressive programs that drive the incredible response in the gay community across America. We know, even coming in, that they have been able to build programs that the rest of the country is often still cautious about.

"When we look at education and prevention programs we also realize that there is a delicate bridge to cross, and that is sex education. We hope this meeting is structured so we learn more about building that bridge," he added. Mr. Kessler is also Executive Director of the AIDS Action Committee of Boston.

The second day people representing the distinctly different Asian, Asian American and Pacific Island populations, which include many racial and ethnic communities, will participate in roundtable discussions. These sessions will cover social and cultural issues as well as provision of services including the specific topics of immigration, sexuality, drug use, religion, familial relations, access to clinical trials, psycho-social needs, education and prevention.

The first day's discussion will include an overview of society's knowledge and attitudes about sexuality and the emergence of "sexually identified" communities and their response to the

epidemic. Discussion will include the impact of these issues on government policy at the local, state and federal levels.

The hearings both days will be held in the Plaza Room of the San Francisco Hilton Hotel, 333 O'Farrell St., starting at 8:30 a.m. Thursday and 8:45 a.m. Friday. A complete agenda is attached.

The Commission has also scheduled time for public comment at 4:30 p.m. on Thursday and 12:15 p.m. on Friday. Those wishing to address the Commission should sign up at the hearing site the day of the hearing.

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of "a consistent national policy" concerning the HIV epidemic.

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members of the Commission are the Secretary of Health and Human Services, the Secretary of Defense and the Secretary of Veterans Affairs.

#

NATIONAL COMMISSION ON AIDS

Hearings

San Francisco, California

San Francisco Hilton Hotel

333 O'Farrell Street

May 16-17, 1991

Agenda

Thursday, May 16, 1991

- 8:30 a.m. Welcome - Honorable Art Agnos, Mayor, City of San Francisco
Opening Remarks - June E. Osborn, M.D., Chair
Remarks - Larry Kessler, Commissioner
- 9:00 a.m. American Society and Sexuality
An overview of knowledge and attitudes about sexuality, and the role sexuality plays in American society.
Reginald Fennell, Ph.D. David Lourea, Ph.D. Pepper Schwartz, Ph.D.
- 10:15 a.m. Break
- 10:30 a.m. The Experience of "Sexually-Identified" Communities
A discussion of the emergence, development and struggles of "sexually-identified" communities. "Sexually-identified" communities are those which are defined by the sexual orientation of their members.
Paul Davis Marjorie Hill, Ph.D.
Sue Hyde Richard LaFortune
Eric E. Rofes
- 12:00 p.m. Lunch
- 1:15 p.m. The Response of "Sexually-Identified" Communities to the HIV Epidemic
A discussion of how "sexually-identified" communities have responded to the HIV epidemic and the impact of that response on American society.
David Barr Paul Bonenberg
Jerome Boyce Valli Kanuha, M.S.W.
Jose Perez Maxine Wolfe
- 2:45 p.m. Break
- 3:00 p.m. Sexuality, HIV and Government Policy
An examination of the impact of society's views on sexuality, the HIV epidemic, and "sexually-identified" communities on the development and implementation of government policy at the local, state and federal level.
Daniel Bross Miguel Gomez
Tim McFeeley Tim Offutt
Carmen Vasquez, M.S.Ed.
- 4:30 p.m. Public Comment Period
- 5:30 p.m. Adjourn

NATIONAL COMMISSION ON AIDS

Hearings

San Francisco, California

May 17, 1991

HIV Disease and Asian, Asian American,
and Pacific Islander Communities

Agenda

Friday, May 17, 1991

8:30 a.m. Opening Remarks - June E. Osborn, M.D., Chair

8:35 a.m. Remarks - Paul Kawata

8:45 a.m. Introduction: Historical Perspective

Gen Iinuma
Tessie Guillermo
Suki Ports

9:30 a.m. Moderator: Jane Po

Roundtable Discussion: Impact of HIV Disease Among Asians, Asian Americans and Pacific Islanders

Kiki Ching
Lei Chou
Billy Gill
Sharon Lim-Hing
Martin Hiraga

Sinh Nguyen
Robby Robison
Merina Sapolu
Paul Shimazaki
Velma Yemota

10:45 a.m. Break

11:00 a.m. Moderator: Fernando Chang-Muy

Roundtable Discussion: Provision of Services

Wayne Antkowiak
Jaime Geaga
Dean Goishi
Kerrily Kitano
Lori Lee

John Manzon
Nga Nguyen
Tony Nguyen
Joanna Omi
Dorothy Wong

12:15 p.m. Public Comment

12:45 p.m. Lunch

2:00 p.m. Commission Business

4:00 p.m. Adjourn

TESTIMONY OF PAUL BONEBERG,
EXECUTIVE DIRECTOR, MOBILIZATION AGAINST AIDS,
TO THE U. S. HOUSE OF REPRESENTATIVES
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
JUNE 6, 1991

HEARING TOPIC:

TEN YEARS OF AIDS: THE PAST AND FUTURE OF THE EPIDEMIC

I am Paul Boneberg and I am here on behalf of the thousands of members of Mobilization Against AIDS. We are an AIDS advocacy group drawn mainly from the Lesbian and Gay Community and have been involved in every major AIDS issue since 1984.

I would like to ask the Subcommittee to consider what might have seemed incredible testimony had this Subcommittee held a hearing on AIDS ten years ago - on June 6, 1981. Would it not have seemed impossible then to have been told:

-that the newly identified disease would in 10 years infect 10 million people worldwide and over 1 million in the U.S.?

-that by today over 110,000 Americans would be dead from it?

-that despite this disaster, two Presidents would have taken little action and the Congress would have seldom appropriated adequate funding for research or disaster relief?

-that an extraordinary volunteer response would have occurred across the nation but would be downplayed because it was led by Lesbian and Gay Americans?

-that some nations would institute needless quarantine for people fighting this disease and even in California quarantine would be placed on the ballot?

-that after a decade, no vaccine would exist and few treatments would exist?

Who would have believed this in 1981?

I submit that in another decade, if current patterns hold, we will have hearings showing:

-hundreds of thousands of Americans dead; two million Americans total infected

quote

-tens of millions infected around the world; dead exceeding 1 million

-widespread disparity of access to medical treatment between the rich and the poor

-massive civil unrest as the infected struggle to obtain the drugs needed to save their lives.

quote { I urge this Subcommittee and this Congress to change the national approach to AIDS to alter the horrific outlook for the next decade. In particular I urge a change in its policy regarding access to treatment.

Mobilization Against AIDS believes that the single greatest issue facing people with HIV infection in the next decade is lack of access to proper medical care, particularly to licensed AIDS drugs.

As you know, billions of dollars have been spent to develop effective AIDS drugs. Equally important is the fact that access to effective AIDS treatment has always been the main priority of people with AIDS. In the early 1980s, thousands of Americans fled to Mexico or France in search of drugs to save their lives. For example, you may recall that Rock Hudson collapsed in Paris while trying to obtain the experimental drug HPA-23. Thousands of people participated in dangerous drug research. In some studies - for example with the drug Suramin - the result was disastrous, leading to the early deaths of many participants. I can recall people having to choose between a drug that might save their lives and a different drug that would save their eyesight.

The price paid by the volunteers for AIDS research in illness, suffering and early death has been very high. It has been paid because only new drugs offer hope against this virus. As a result of these efforts a number of AIDS treatments have been licensed, most prominently the drug AZT.

quote { Given the high price paid in federal dollars and human suffering, it is appalling to observe that even the most widely used of licensed AIDS medicines are not reaching even 1/3 of those who need them. The CDC estimate that of the 1 million Americans infected with AIDS, over 600,000 have 500 T-Cells or less and need to be on AZT. However, in 1990 Burroughs-Wellcome offered so little AZT for sale that if everyone who took the drug took only the minimum dosage and there was no waste, only 80,000 people could have received the drug. I repeat, no more than 80,000 out of the 600,000 who needed AZT received it last year.

Another example is continuing cases of pneumocystis pneumonia, a disease which is preventable in over 90% of people by the use of the drug aerosolized pentamidine or the drug Septra. However, in California in 1990 nearly half - 47.5% - of people with AIDS had a bout of pneumocystis. This could only have occurred with treatment that was grossly inadequate.

These are the best known and most widely used drugs, so we can confidently assume that other existing medications or any new drugs must have even smaller usage.

Why is this occurring? Two Reasons:

1. Most Americans are not convinced that HIV infection can be treated so they do not get tested to find out if they are infected. Even many who know of their infection do not seek treatment because they are convinced that they will soon die.

2. Many members of communities at risk for infection believe that if they test positive, they will be put on lists used to deny HIV-infected people their jobs, homes, or liberty. Every time a mandatory testing proposal is made - such as the AIDS quarantine ballot initiative in California in 1986 or the current ban on free travel for infected foreign visitors - our ability to get people to seek treatment and be tested is harmed.

To correct the dearth of those receiving licensed AIDS drugs, we must expand the educational efforts which inform people of the benefits of early treatment. We must expand efforts for people to voluntarily be tested as part of seeking treatment, and we must defeat efforts to force people to be tested, to compile lists of those exposed, or to punish people simply because of their illness.

The second issue of great importance to people fighting AIDS is faster and broader access to AIDS drugs which by today's definition would be labelled experimental. Too often, treatments which are clearly beneficial are stalled in the internal processes of the FDA, the manufacturer or both. For example, it was known by some physicians that aerosolized pentamidine was highly effective in preventing pneumocystis for years before it was licensed. It was clear that AZT was beneficial in early treatment, yet many hospitals had to wait for their patients to develop full-blown AIDS before prescribing the drug due to lags in FDA licensure. Again and again it was demonstrated that the informed and wealthy patient received experimental drugs on the verge of licensure and lived, while the uninformed or the impoverished did not receive treatment and died.

The Food and Drug Administration seems highly accountable for keeping dangerous AIDS drugs from killing people. Unfortunately, their accountability for the lives of those who die while waiting for promising drugs to come to market is somewhere between inadequate and non-existent.

The nation must reform its approval process for drugs for life-threatening diseases. Mobilization Against AIDS believes that once a drug is demonstrated to be safe and there is good indication of effectiveness, then it must be made widely available to patients and their physicians. The current parallel track and compassionate use programs are inadequate. We urge this committee to assist FDA

Commissioner Kessler in devising a new, broader plan for drug availability. We see conditional approval of drugs for life-threatening disease as one viable option and urge this Subcommittee to consider it. We hope that action can be taken quickly by Administrative reform but if this is not quickly forthcoming, we urge this Congress to solve the problem with legislation. It is clear to us that tens of thousands of Americans need immediate access to drugs now labeled experimental. They are literally at the end of their chemical ropes. We need to take bold action to assist them.

In my limited remarks I have addressed only the issue of access to medication for Americans, which my organization sees as of paramount importance. However, we also strongly support increased efforts at AIDS education and prevention and increased research for AIDS and all life-threatening diseases.

We recognize further that the solution to AIDS is part of the overall health crisis in America - a crisis which requires access to health care for all citizens.

In closing, let me note that in 1981 AIDS activists had neither organizations nor treatments nor scientific research nor tests for infection. Our poverty of resources was so complete that we did not even have a name for the disease we were fighting.

Now, after 10 years, we have information that is useful - if it can be dispensed; drugs that are life-prolonging - if they are made available; and many scientists who can develop better treatments - if they are given adequate resources. Yet even as we speak, in other parts of this Capitol, the Appropriations Committee of this Congress is deciding not to fully fund AIDS research, not to provide disaster relief.

I wish to add my voice in this most formal of records to protest the continuing inadequacy of the response of the Federal government to AIDS. This planned policy of neglect will cost the lives of hundreds of thousands of Americans and millions of others around the planet. The deaths of so many people are not being caused by lack of scientific advances but instead by lack of vision and political courage.

It is my sincere hope that before the next AIDS milestone and the next macabre anniversary, the will of this nation and its leadership will change.