

CHRISTMAS CANCELLED!

**Santa is sick with HIV-infection.
NO DELIVERIES THIS YEAR**

**Santa gave the virus to Mrs Claus.
NO COOKIES THIS YEAR**

**IF ONLY REAGAN AND BUSH HAD TOLD THE TRUTH,
SANTA WOULDN'T HAVE TO DIE FROM AIDS.**

Future Directions in AIDS Research *Toward a Cure . . .*

CONSENSUS STATEMENTS

JULY 30-31, 1993

Premise: We believe that effective treatments will be discovered for this disease. We are committed to the belief that it is possible to develop new therapies within a reasonable time capable of providing long-term survival without clinical disease.

1. Insufficient resources inhibit the pace of both general biomedical research and AIDS-specific research. More resources will shorten the time to develop effective treatments
2. There is an unmet need to identify gaps or discontinuities in programs of research and in the implementation of clinically relevant findings.
3. Targeted special programs should be considered for emerging, gap-filling, or risky innovative research areas. Mechanisms for prioritization are possible and should be utilized.
4. There is a need to improve communication pathways and coordination among investigators. One example is the need to develop high quality repositories for defined clinical samples.
5. The urgent challenge of AIDS highlights the problem of constituting complex drug trials using multiple proprietary compounds from distinct public and private sources. A rational and comprehensive strategy should be implemented to overcome barriers at all levels that mitigate against these novel therapeutic trials. This point addresses the crucial problem of initiating therapeutic studies with multiple, simultaneous agents owned by different entities.
6. There is a need for the further stimulation and support of creative thinking in the AIDS research community. This should include an assessment of different management styles and structures and an emphasis on the training of new investigators.
7. There is need to expand and create AIDS research programs by infusion of money and talent from outside the current NIH structure.
8. The government should work with industry to create a mechanism to attract the pharmaceutical industry to participate in these efforts.
9. The President, his Administration and Congress must take a leadership role in educating the American public and world community on why these initiatives are important and urgent.

No amount of structural review or proposals for change will work without first defining the mechanism for implementation and then finding the will and courage to carry them out.

Facilitating Organizations:

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Future Directions in AIDS Research

Toward a Cure . . .

On July 30 and 31, 1993 a historic meeting was convened at the University of Wisconsin, Madison, to address the current state of AIDS Research and to look at potential improvements in the direction of research efforts for the future. The 40 attendees included leading American AIDS researchers, from both the government and academia; representatives of community AIDS groups nationwide; industry and regulatory representatives; and representatives of the US government who would have a role in implementing recommended policy changes. Kristine Gebbie, the National AIDS Policy Coordinator, made one of her first public appearances in her new position to attend the meeting.

The meeting was prompted by Project Inform founder Martin Delaney's call for an assessment of the state of AIDS research and suggestion for a targeted research effort. Many attendees were invited to participate because they had also called for either an assessment or a directed research effort; some participants had proposals for change in hand, while others expressed caution yet were willing to put the issues on the table. With such a diverse group, the discussion was lively, intense, and often surprisingly in agreement.

The first day of the "think tank" focused on identifying critical research questions necessary to answer in order to advance the current state of AIDS research. Issues included the need to intensify research in the areas of gene therapy, immune reconstitution, specific questions of pathogenesis and the development and standardization of sensitive assays to measure viral load.

The second day turned towards examining various obstacles to hastening the pace of AIDS research and developing constructive solutions. Among a number of recommendations was the need for a more collaborative effort and a higher level of information exchange among all parties involved in AIDS research. Participants developed consensus on a number of issues, including the need for incentives to develop more creative approaches to AIDS research and an increase in budgets for both biomedical research in general and AIDS research in particular.

The meeting, chaired by June Osborn, former Chair of the National Commission on AIDS, was highly successful. It was agreed at the end of the two days that the discussion was not finished, that much work remained to be done, and that the group should reconvene in November to create a concrete list of scientific and policy suggestions for new directions in AIDS research.

Project Inform participants and/or assistants included Martin Delaney, Brenda Lein, Joel Thomas, Jesse Dobson, Anne Donnelly, and David Lewis.

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DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Food and Drug Administration
Rockville MD 20857

September 28, 1993

Dear Colleague:

I am very pleased to announce the creation of the Food and Drug Administration (FDA) Office of AIDS and Special Health Issues.

This Office will serve several critical functions within the FDA. First of all, it will continue to be a major contact point between the FDA and people with AIDS, and take on additional work as a liaison for people with other serious and life threatening diseases. Secondly, it will be a point of contact between the FDA and other federal agencies dealing with these diseases. Thirdly, where appropriate, this Office will attempt to represent, within the FDA, the perspectives of people with these diseases.

This Office is an outgrowth and an expansion of the Office of AIDS Coordination which has carried out these activities over the past four years. The creation of the Office of AIDS and Special Health Issues in no way represents a diminution of the FDA's commitment to issues related to AIDS. We believe we have learned a great deal through our work with the AIDS community, and want to extend these efforts to other groups. Additional staff will be added to the existing office to allow it to broaden its scope and to provide comparable services to people with other serious diseases.

Dr. Randolph F. Wykoff who has been the Director of the Office of AIDS Coordination since its inception, will serve as the Director of the Office of AIDS and Special Health Issues. The existing staff of the Office of AIDS Coordination will remain intact, with additional personnel joining them in the near future.

We sincerely hope that this move is a positive step forward in continuing effective dialogues between the FDA and the constituents that we serve. I look forward to your thoughts and comments on how this Office can most effectively meet your needs and the needs of your organization. Please do not hesitate to contact the Office of AIDS and Special Health Issues at (301) 443-0104 or by FAX at (301) 443-4555.

We look forward to working with you.

Sincerely yours,

A handwritten signature in cursive script, reading "Carol R. Scheman", is written over a horizontal line.

Carol R. Scheman
Deputy Commissioner
for External Affairs

Enclosure

membership on one or more of the advisory committees. Nominations shall specify the committee for which the nominee is recommended. Nominations shall state that the nominee is aware of the nomination, is willing to serve as a member of the advisory committee, and appears to have no conflict of interest that would preclude committee membership. Potential candidates will be asked by FDA to provide detailed information concerning such matters as financial holdings, consultancies, and research grants or contracts in order to permit evaluation of possible sources of conflict of interest.

This notice is issued under the Federal Advisory Committee Act (5 U.S.C. App. 2) and 21 CFR part 14, relating to advisory committees.

Dated: August 19, 1993.

Jane E. Henney,

Deputy Commissioner for Operations.

[FR Doc. 93-20633 Filed 8-25-93; 8:45 am]

BILLING CODE 4160-01-F

Statement of Organization, Functions, and Delegations of Authority

Part H, Chapter HF (Food and Drug Administration) of the Statement of Organization, Functions, and Delegations of Authority for the Department of Health and Human Services (35 FR 3685, February 25, 1970, as amended most recently in pertinent part at 56 FR 29484, June 27, 1991) is amended to reflect the abolishment of the Office of Science and the transfer of science functions, except for AIDS coordination, to the Office of Operations. FDA believes that this realignment of science functions within FDA is necessary to integrate fully the science and operational functions of the Agency.

The Office of AIDS Coordination will be retitled as the Office of AIDS and Special Health Issues and relocated from the Office of Science to the Office of External Affairs. The reorganization expands the Office of AIDS Coordination to include similar support for other special health issues such as cancer and Alzheimer's disease. The purpose of the expansion is to facilitate Agency coordination and communication on special health issues and associated advocacy groups.

Under section HF-B, Organization:

1. Delete paragraph Office of Operations (HFA9) in its entirety and insert a new paragraph reading as follows:

Office of Operations (HFA9). Advises and assists the Commissioner and other key officials on compliance-oriented matters.

Develops and administers all Agency field operations and provides direction and counsel to Regional Food and Drug Directors.

Administers regulation of biological products under the biological product control provisions of the Public Health Service Act and applicable provisions of the Federal Food, Drug, and Cosmetic Act. Works to develop an Acquired Immune Deficiency Syndrome (AIDS) vaccine and AIDS diagnostic tests, and conducts other AIDS-related activities.

Develops and administers programs with regard to the safety, effectiveness, and labeling of all drug products for human use.

Develops and administers programs with regard to the safety, composition, quality (including nutrition), and labeling of foods, food additives, colors, and cosmetics.

Develops and administers programs with regard to control of unnecessary exposure of humans to, and assures the safe and efficacious use of, ionizing and non-ionizing radiation-emitting electronic products.

Develops and administers programs with regard to the safety, effectiveness, and labeling of medical devices for human use.

Develops and administers programs with regard to the safety and effectiveness of animal drugs, feeds, feed additives, veterinary medical devices (medical devices for animal use), and other veterinary medical products.

Manages the implementation of the provisions of the Orphan Drug Act.

Advises and assists the Commissioner with regard to research programs being conducted to study the biological effects of potentially toxic chemical substances found in the environment to determine the adverse health effects resulting from long-term, low-level exposure to chemical toxicants in animal organisms, to develop improved methodologies and test protocols for evaluating the safety of chemical toxicants, and to develop data to facilitate the extrapolation of toxicological data from laboratory animals to man.

The Office of Operations includes the: Office of Regulatory Affairs (HFA4), Regional Field Offices (HFR), Center for Biologics Evaluation and Research (HFB), Center for Drug Evaluation and Research (HFN), Center for Food Safety and Applied Nutrition (HFF), Center for Devices and Radiological Health (HFV), Center for Veterinary Medicine (HFV), Office of Orphan Products Development (HFA-E), Office of Biotechnology (HFA-H), National Center for Toxicological Research (HFT).

2. Insert a new subparagraph under Office of External Affairs (HFAQ) reading as follows:

Office of AIDS and Special Health Issues (HFA5). Serves as an information resource to FDA and provides advice to the Commissioner, Deputy Commissioners, and other senior FDA staff on matters related to AIDS, cancer, Alzheimer's Disease and other special health issues.

Coordinates interactions between FDA and consumer and professional groups dealing with AIDS, cancer, Alzheimer's Disease, and other special health issues.

Serves as a liaison point to coordinate contacts between FDA and other federal agencies to ensure effective coordination and communication on AIDS, cancer, Alzheimer's Disease, and other special health issues.

Provides internal coordination on FDA activities related to AIDS, cancer, Alzheimer's Disease, and other special health issues.

Assists in the planning, administration, development, and evaluation of FDA policies related to AIDS, cancer, Alzheimer's Disease, and other special health issues.

3. Delete paragraph Office of Science (HFAH) in its entirety.

Prior Delegations of Authority. Pending further delegations, directives, or orders by the Commissioner of Food and Drugs, all delegations of authority to positions of the affected organizations in effect prior to this date shall continue in effect in them or their successors.

Dated: August 18, 1993.

Donna E. Shalala,

Secretary.

[FR Doc. 93-20723 Filed 8-25-93; 8:45 am]

BILLING CODE 4160-01-M

Public Health Service

National Institutes of Health

Privacy Act of 1974; New System of Records

AGENCY: Public Health Service, HHS.

ACTION: Notification of a new system of records.

SUMMARY: In accordance with the requirements of the Privacy Act, the Public Health Service (PHS) is publishing a notice of a new system of records, 09-25-0168, "Invention, patent and licensing documents submitted to the Public Health Service by its employees, grantees, fellowship recipients and contractors, HHS/PHS/NIH/OTT." We are also proposing routine uses for this new system.



AHEAD

Alliance for the Health of Adolescents

**SPECIAL
PROGRAMS
FOR YOUTH**

S.F.D.P.H.

375 Woodside Ave

San Francisco

California 94127

415-753-7786

Dear Friends,

09/01/93

Enclosed is the first issue of **REALITY** (REAL Ideas and Thoughts by and for Youth). This newsletter is intended for young people who are living with HIV or AIDS, but I am sure that all youth could benefit from reading this newsletter. We are hoping that this will reach as many young people as possible so that they can read about others like themselves and may also want to contribute something that can be published. Therefore, if you would like to Xerox this copy, please feel free to do so.

We are asking for donations of \$20.00 or more to help cover the costs of duplication. If you are able to donate money, please make your check out to **Project AHEAD-Friends of the Health Department**.

We are planning our second printing to be coming out sometime in September/October. Thank you for your interest in this newsletter. We hope that this will be one way to help end isolation of young people living with HIV.

If you have any questions please feel free to call me at 415/753-7875 ext. 7875. Our address is:

REALITY
Project AHEAD
375 Woodside Avenue
San Francisco, CA 94127

Sincerely,

Antigone Hodgins
Project Assistant
Project AHEAD

Future Directions in AIDS Research

Toward a Cure...

AIDS LEADERS MAP NEW DIRECTION IN AIDS RESEARCH

(Boston, MA) November 23, 1993 -- For the first time in the history of the AIDS epidemic, AIDS researchers, government officials, pharmaceutical industry leaders and AIDS activists have formally agreed that a coordinated program of both public and private research is the direction that the search for effective treatments must take.

Meeting in Boston this weekend, leaders from these groups pledged to reinvigorate AIDS research in light of the most recent International Conference on AIDS, held in Berlin in June. Dubbed "The Madison Project," from its initial meeting site, the Future Directions in AIDS Research (FDAR) conference ended today with agreements to increase innovation and coordination to accelerate the pace of AIDS research and, in an historic move, to advocate for the immediate implementation of these recommendations listed below.

Organized by the Harvard AIDS Institute, Project Inform, and the University of Wisconsin at Madison, the group adopted specific strategies outlined in a conference report. Among the highlights of these strategies were:

- *All participants* agreed to the creation of a scientific task force to develop strategies that immediately tackle the critical questions related to innovations in AIDS research. this task force would not only present its findings to public agencies such as the office for AIDS Research and the National Institutes of

- - more - -

Health, but would also facilitate collaborations with the private sector that would not otherwise occur.

- *The pharmaceutical industry*, represented by the Inter-Company Collaboration of pharmaceutical companies, will create the first draft of a plan needed to push ahead new drug trials involving multiple agents owned by the separate companies.
- *The academic and governmental community* agreed that state-of-the-art telecommunications and further development of electronic information systems specific to AIDS research are required to accelerate communication dramatically, increase productivity and reduce redundancy.
- *All participants* agreed that a coordinated effort to include training and more facile communication must be established to increase collaboration among basic research fields, including those not presently considered to be AIDS related.
- *Key participants and conference organizers* agreed that a targeted new team-oriented effort focused on a designated research area operating under a unique grant system and funded with new moneys beyond the NIH's current AIDS research effort would operate with unprecedented speed and flexibility.
- *All participants* agreed that funding for the implementation of these recommendations should come from new resources rather than detracting from current biomedical research funding.

- - more - -

The Future Directions in AIDS Research conference series, of which the Boston meeting was the second, draws together top researchers, government officials, pharmaceutical industry leaders and AIDS activists from across the nation. This conference was organized into working groups whose chairs included Dr. Richard Marlink of the Harvard AIDS Institute, Dr. David Pauza of the University of Wisconsin at Madison, and Martin Delaney of the San Francisco-based advocacy group, Project Inform. Through weekend-long private meetings in July and November, the group agreed that effective treatments for AIDS are within reach, and from that premise moved to identify and overcome barriers to finding those treatments. The project now has a working report that outlines its recommendations, and the organizers plan to rally both public and private support for these strategic items.

Implementation of the strategies was given a significant boost by a \$125,000 seed grant from the Design Industries Foundation for AIDS (DIFFA) and Broadway Cares/Equity Fights AIDS. Above and beyond the initial \$125,000 to encourage partnerships and collaborations in the community, DIFFA and Broadway Cares/Equity Fights AIDS have also issued a \$125,000 challenge grant to encourage other major funders to participate in the process through which the recommendations will be implemented.

#

Think Tank Helping to Get HIV Immune-Restoration Trials Off the Ground

DURING THE NEXT 6 months, a change in emphasis in research on HIV disease should begin to take hold.

Work that focuses more on repairing the damaged immune system than on directly killing the human immunodeficiency virus (HIV) shifts into high gear.

The necessity of both treatment approaches has been evident since the early days of the AIDS epidemic. But research on immune restoration languished after the approval of the antiretroviral drug zidovudine (Retrovir, commonly called AZT, Burroughs Wellcome, Research Triangle Park, NC). What trials were done had disappointing or equivocal results.

The pace is picking up now, in large part due to a unique think tank called Project Immune Restoration. It is made up of a broad array of researchers, government officials, and activists who, for the past 18 months, have focused intensively on finding out what can be done in the clinic now and what needs to be done in the laboratory for further progress to take place. The unique effort was shepherded by Jesse Dobson of Project Inform, who died of AIDS-related disease in September, just as concrete evidence of its success was beginning to emerge.

Rave Reviews

Participants raved after the think tank's latest meeting last month in Baltimore, Md, about the rare opportunity it is providing to translate ideas into action much more quickly than they otherwise could. Immune-cell-based therapies in particular are leapfrogging from the laboratory into the clinic.

In this next year "there are going to be many cell-therapy trials started for the first time" in HIV disease, says Thomas Merigan, MD, professor of medicine at Stanford University, Palo Alto, Calif.

"This field is moving fast. We all heard



Jesse Dobson is credited by researchers involved with Project Immune Restoration for its success. He died of AIDS-related disease in September.

things we have not heard before," says Robert (Chip) Schooley, MD, chief of infectious diseases at the University of Colorado School of Medicine, Denver, and chair of the immunology committee for the National Institute of Allergy and Infectious Disease's AIDS Clinical Trials Group.

The think tank meetings differ from most medical conferences. "Instead of talking about things we have done, we talk about things we would like to see done. And with so many people here brought together specifically because of their different areas of expertise, you can build together a team that can actually do these things," says Schooley.

Controversial concepts get a more constructive airing as well, says Stella Knight, PhD, head of the Division of Antigen Presentation Research at Great

Britain's Clinical Research Center, Harrow, Middlesex.

Knight's work suggests an important role for dendritic-cell depletion, which precedes the better known depletion in T cells in HIV pathogenesis. She believes this is important because dendritic cells "teach" naive T cells how to respond to antigen; but she acknowledges that her theory is "still questioned by many."

However, at the Project Immune Restoration meeting, "instead of spending energy questioning the concept, you go with the concept, discuss how it might integrate into a greater picture, and see whether it is useful. We can be open without fear of immediate contradiction or condemnation before we've had a chance to look at where the ideas lead, and devise strategies for those working in areas that may be controversial but still need to be worked on," she says.

Integrated Picture

"You get an integrated picture without the nitpicking," says Knight, adding that she now has a much clearer sense of where her work, if confirmed, would fit in with the overall picture of other cell-population irregularities in HIV disease.

"People don't learn very well when they're on the defensive," says Martin Delaney, director of Project Inform. "A lot of science puts people on the defensive rather than opening their minds to each other's work. We're trying to get these people from all disciplines who work on these different pieces in different ways to come together and look at it as a whole," says Delaney.

There is still a great need to "more precisely define what's broken in the immune response in AIDS," says Delaney. While that may seem obvious, "it is much more complicated than a loss of CD4 cells. We're looking on one hand at sustaining what's there and prevent-

ing more damage, and then on rebuilding what's broken."

Jonas Salk, MD, who developed the first polio vaccine and is working on HIV therapeutic vaccines, says participating in the Project Immune Restoration think tank "reminds me of the days when the National Foundation for Infantile Paralysis focused its attention on resolving that problem."

Concrete Proposals

Schooley says Project Immune Restoration provides not only a "renewed sense of hope" for understanding how HIV causes immunodeficiency, and a wider view of things that might reverse the immunodeficiency in late-stage HIV disease, but "concrete proposals that will actually lead to things that otherwise would not have been done."

"There are 15 million people infected with the virus around the world, and many are reaching the stage where even if we had a magic tablet that would get rid of the AIDS virus, many would still not be able to survive simply because too much damage has been done to this vital [immune] system," says John Dwyer, MD, PhD, head of the Department of Medicine at Prince of Wales Hospital, Sydney, Australia.

"As a result of our deliberations, we have a half dozen or so very practical strategies that can be worked on in the next year to see if we can't correct some of those deficiencies, extending life and the quality of life considerably," says Dwyer.

Mark Harrington, an activist with the Treatment Action Group in New York, NY, concurs that "there is consensus that we can get protocols up and start this process of shoring up the immune system while we're waiting for the perfect antiviral."

Expanding Cell Expansion

What can be expanded right away are cell-expansion studies, in which immune cells are taken from patients while they are still healthy, grown in culture, perhaps augmented in a variety of ways, stored, and then reinfused in the late stages of disease.

Dwyer's laboratory has harvested cells from 50 patients at various stages of infection and is "sitting back and waiting for the time when it would be appropriate to give the cells back, and trying in the meantime to work out the best strategies for when to give them."

Participants in Project Immune Restoration "deliberately kept our thinking to things that modern-day knowledge and technology will allow us to do." With investigators from the United States and elsewhere likely to "pick up on our pro-

ocol and do the same sort of things, we'll all get the answers we want that much faster."

Dwyer is not separating the different components of the harvested blood cells, because "we're not sure which cells are most important, and we thought it seemed a good strategy as a starting point to say that since the patients we're taking cells from are perfectly well, their cells are in balanced proportion, so we will try to give them all back and see what happens." If it works, then storing cells early in infection will be like "an insurance policy" for patients, he says.

Dwyer also wants to try immunizing patients with Salk's vaccine to boost anti-HIV activity before harvesting cells.

There are many variations on the cell-expansion approach. Expansion and reinfusion of CD8 cells has been under way for 2 years.

A clinical protocol for expansion of CD4 cells is in review now at The Johns Hopkins University School of Medicine, Baltimore, Md. Researchers at Stanford University are working on getting support for a protocol using expansion of CD4, CD8, and dendritic cells.

Investigators at Tufts University School of Medicine, Boston, Mass, are separating out only cells that are specifically active against individual patients' own strain of HIV. Judy Lieberman, MD, PhD, is mapping the small number of short (eight to 10 amino acid) peptides on the virus that T cells actually recognize, which varies from patient to patient. She then cultures only the T cells with receptors for those peptides, multiplies them in vitro, and reinfuses them, so far into nine patients. Similar work that uses cloning to get large numbers of virus-specific T cells is set to begin soon at the University of Washington in Seattle.

There are also several proposals for somehow beefing up cells while they are in culture, either with cytokines or genetic alterations, though these approaches are not as near to clinical testing.

Ethics and Logistics

The logistics and ethics of cell-expansion therapy are going to be addressed at a meeting being planned for early next year by John Kagan, PhD, chief of the clinical science section, Division of AIDS at the National Institute of Allergy and Infectious Disease.

Repositories will be needed to store frozen cells, and "since we would probably not have the capacity to offer this to as many patients as would potentially want it, the ball starts rolling on ethical issues of access and a whole bunch of

reasons for which there could be difficult questions arising," says Kagan. He adds that there is "probably no shortage of folks out there already ready to prey on the wishful thinking of AIDS patients, and take their money to store their cells with some promise of a treatment" that may not come.

Kagan is also hoping to schedule two other meetings on cell therapy. One, which he says he may hold yet this year, will be to discuss whether evidence from about a half dozen anecdotal reports of allogeneic blood lymphocyte transfer between half-matched (sibling) donors is enough to warrant a formal trial.

Second, Kagan is working on a 2-day meeting for early 1994 to discuss stem-cell transplant possibilities, including bone marrow and peripheral blood stem cells. The goal would be to determine the best direction for basic research on such things as whether stem-cell maturation is dependent on the thymus, which is severely damaged in patients with AIDS.

There is great heterogeneity of opinion about whether patients with HIV have all the things necessary for the development of cells, and whether that might explain why bone marrow transplant trials in HIV disease have been so disappointing, says Kagan.

Laboratory groundwork for trying thymus transplants again is being laid, says Dwyer. Experiments by him and others in the mid 1980s in 18 patients were "tried and failed and put aside. Any immune cells that were generated were soon killed; the virus more or less said thanks very much, here are more T cells to destroy," he recalls.

But while there are still a number of technical problems to work out, there have been enough advances in knowledge that investigators now think they may be able to get new cells in transplanted thymus tissue to fight the virus in a new host, says Dwyer. "It's now at the stage where it is worth researching again."

Also, looking at the long-term picture, there is a surprising amount of interest in the possibility of xenogenic transplants.

Kagan says many at the Baltimore meeting have responded to a request for applications from his institute for new research programs that combine innovative basic research with preclinical work "so as to hasten the development of novel therapies into clinical trials."

"Maybe a lot of these protocols initially will not save patients," says Delaney, "but we will learn something that will make it possible to save the next patient."—by Paul Cotton

FUTURE DIRECTIONS IN AIDS RESEARCH- "THE MADISON PROCESS" A History

While many voices have been calling for a more aggressive approach to AIDS research since the middle 1980s, the latter half of 1992 and the first half of 1993 saw a tremendous increase in the fervor for such a change. For some people, the concept was manifest in a so-called "Manhattan Project." That is, the notion that a highly-focused research program might be created which mimicked at least the sense of urgency demonstrated by the famous project which created the first atomic bombs. This approach was most concretely demonstrated by several editorials published by Larry Kramer, and by the creation of the Barbara McClintock Proposal by a faction of ACT UP/New York. Other voices saw problems with the analogy, but most agreed with the spirit that indeed more could be done. Some of the interest in change took the form of the Office of AIDS Research reform bill, which was eventually passed by the U.S. Congress. Although supportive of this internal NIH reform package, still other voices urged even more sweeping actions. Many of those voices were quoted in the special AIDS issue of *Science Magazine* which preceded the VIII International AIDS Conference in Berlin in June of this year. At the very least, it is fair to say that the interest in aggressive, palpable change was demonstrated by patients, researchers, activists, and governmental people alike.

From the fall of 1992 through the first half of 1993, discussions about how to turn this talk into action began independently in various quarters. Discussions between individual scientists, within and outside of government, quickly led to the discovery that at least two groups were preparing to propose the creation of a process or meeting in which these issues could be raised. In particular, the Harvard AIDS Institute had developed a proposal to hold a conference, with a special interest in discussing the National AIDS Research Agenda and new approaches to communication between researchers. Simultaneously, Project Inform was discussing the possibility of calling a conference which built upon the successful model of its Immune Restoration Think Tanks, a unique privately-sponsored setting which seemed to stimulate valuable input and planning from top scientists. Because the planning for these two events included overlapping personnel and goals, the ideas were joined into a single plan.

Because both the Harvard AIDS Institute and Project Inform were already widely engaged in the public and scientific fight against AIDS, it was felt that the hosting of any first conference would best be left in the hands of a third party and at a site not associated with the status quo. For this reason, the Harvard/Project Inform team contacted Nobel Laureate Howard Temin at the University of Wisconsin at Madison, and asked if he would serve as the conference host. Later, due to health concerns, Dr. Temin passed the responsibility on to Dr. David Pauza of the University of Wisconsin Primate Research Center, who in turn began coordinating all efforts with the staffs of Project Inform and the Harvard AIDS Institute. Throughout the planning period, the three organizations were supported and advised by a core team of researchers both in and out of government.

The purpose of the initial conference was to bring together those voices in the AIDS research, policy, and activist communities who were calling for an aggressive new reevaluation of AIDS research, in hopes of creating a unified voice about how to proceed. Dr. June Osborn, former head of the National Commission on AIDS, joined this effort as an advisor and facilitator for the meeting.

Because all present at the first meeting in Madison felt that effective treatments will someday be developed for HIV disease, the goal of the process became much clearer: How can we achieve those treatments more quickly together, rather than separately through only traditional channels? The first meeting, therefore, concluded with the development of a list of consensus statements, describing unmet needs and opportunities for progress. Subsequently, four working groups were formed to turn the consensus statements into policy and action proposals. Those proposals will be presented and debated at the second meeting in Boston, with the hopes of making specific recommendations from the group not only for the Clinton Administration, but also for all of us involved in the effort to end this epidemic.

Cooperative research

New projects targeted to fill gaps in AIDS knowledge

By Sari Staver
AMNEWS CORRESPONDENT

SAN FRANCISCO — Last summer, 50 leading HIV experts held an unusual two-day "think tank" in Madison, Wis., to study ways to improve AIDS research. The participants ranged from T-shirted activists to button-down drug industry executives and government officials.

A second gathering is planned for next month, after which the group says it will present the Clinton administration with a set of recommendations.

The meeting, called historic by organizers, reflects a growing spirit of cooperation and collaboration among AIDS experts, long united in their dedication to battling the decade-old epidemic but frequently at odds over strategy and style.

Fueling this trend is the view among some authorities that the pace of research has been unacceptably slow, said Derek Hoedel, treatment issues director for the AIDS Action Council, an advocacy group based in Washington, D.C. Frustration only increased during this year's international AIDS conference in Berlin, where report after report noted the limited efficacy of current treatments.

"Scientists and regulators are now willing to consider any option that offers a chance for progress," Hoedel said.

The efforts, aimed largely at identifying and addressing gaps in research, have created some scenarios unimaginable in years past: government scientists and policymakers setting research agendas in partnership with anti-establishment activists, and rival pharmaceutical manufacturers collaborating to conduct clinical trials.

Jeffrey Laurence, MD, senior scientific adviser to the American Foundation for AIDS Research, says the time is right, scientifically, for such efforts. Until now, "we didn't know what we didn't know" about the human immunodeficiency virus, he explained. "Now we seem ready to target the questions that need to be answered."

Building bridges

Among the cooperative efforts:

■ Fifteen pharmaceutical companies have formed the Inter-Company Collaboration for AIDS Drug Development to facilitate trials of combination drug therapies against HIV. The manufacturers will share information and supplies so that each individually can conduct early-stage combination studies.

■ Consortium coordinator Linda Distelrath, PhD, senior director of public policy management at Merck & Co., traced the unprecedented industry collaboration

to three factors: the recognition that HIV apparently develops resistance over time to all antivirals; the increase in the number of potential treatment compounds; and the evidence that multidrug combinations might mitigate the resistance problem.

■ More than 40 physician networks are conducting AIDS clinical trials with government or private-sector funding.

One of the largest is the 10-year-old County-Community Consortium of AIDS Physicians in San Francisco, created originally to inform private physicians about the clinical trials available to their patients at San Francisco General Hospital. Over time, however, it became clear that some trials might be done more effectively in doctors' offices, said Donald I. Abrams, MD, who heads the effort.

For example, "more and more, we realize that one of the missing pieces of information is data on longer-term outcomes, including survival" of patients taking antivirals, he said. Community-based primary care physicians are most likely to stay with patients long enough to provide such longitudinal data.

"Studies now under way on the treatment and prevention of common opportunistic illnesses could greatly improve the quality of life of our patients. I think we will find our greatest impact in helping practitioners learn to better manage this disease."

■ Since the late 1980s, the National Institutes of Health, the Food and Drug Administration and dozens of pharmaceutical companies have included AIDS activists on advisory panels that help guide trials.

Their presence has led to improved clinical trials, said Jack Killen, MD, acting director of the Office of AIDS at the National Institute of Allergy and Infectious Diseases. For

example, input from activists enabled federal investigators to enroll more women in a major antiviral drug trial, ACTG 175. The activists pointed out that the eligibility criteria did not account for the physiological differences between men and women, and thus inadvertently excluded women. The criteria were then altered, Dr. Killen said.

■ The Ariel Project, a three-year, \$15-million research effort sponsored by the Pediatric AIDS Foundation, is studying 150 HIV-infected, pregnant women at seven sites nationwide. The goal is to determine the virologic and immunologic factors influencing mother-to-child HIV transmission. The project was developed by a multidisciplinary board of physicians and scientists representing government, academia and the drug industry, who identified this area as one that

See AIDS, page 48

**'It is ironic that
it took a
community-based
organization to
bring together
such a group to
do what we've
needed to do all
along — talk to
each other in a
cooperative,
constructive
manner.'**

ROBERT SCHOOLEY, MD

AIDS

Continued from page 2

had been insufficiently addressed in previous research.

■ **Project Immune Restoration**, a 2-year-old initiative by the San Francisco-based advocacy group Project Inform, has held two think-tank-style gatherings to set research priorities for treatment of late-stage HIV-disease, another area in which they say not enough research has been focused. Participants called for studies of the role of thymic transplantation, gene therapy, *ex vivo* cell expansions and xenogenic tissue transfer. They are seeking interest from public and private sector investigators. A third meeting, scheduled for November, will address regulatory, funding and other implementation concerns.

"Meetings like these should have been held throughout the first 12 years of the epidemic," said Robert Schooley, MD, head of infectious diseases at the University of Colorado School of Medicine and a member of the initiative's expert panel. "It is ironic that it took a community-based organization to bring together such a group to do what we've needed to do all along — talk to each other in a cooperative, constructive manner."

Model for change

But perhaps the most promise for change is seen in the meeting held in Madison, which was organized by the University of Wisconsin Medical School, the Harvard AIDS Institute and Project Inform. Participants ranged from Larry Kramer, founder of the radical advocacy group ACT-UP, to federal AIDS policy coordinator Kristine Gebbie; Commissioner David A. Kessler, MD, of the Food and Drug Administration; and Anthony M. Fauci, MD, director of the National Institute for Allergy and Infectious Diseases.

Gebbie described the meeting as "very significant, because it was the first time such an intriguing mix of people met together in a productive atmosphere."

Said organizer David Pauza, PhD, associate professor of medicine at the University of Wisconsin, Madison, "It is not unfair to characterize this as an historic meeting that begins a new process to reinvigorate our fight."

In broad-based discussions, the group reached consensus on several points. Chief among those was that insufficient resources are the primary obstacle to research progress, said Richard Marlink, MD, executive director of the Harvard AIDS Institute. A variety of approaches were suggested for boosting financial support, from marshaling a more organized private response, like the March of Dimes and American Cancer Society have done, to forming a public-private consortium, or "Manhattan Project," that would collect, prioritize and disperse all resources to fight the disease.

The group also noted the need for a mechanism to encourage drug companies to assume the risk for developing a larger number of basic scientific findings, many of which now languish in academic or government research laboratories.

Martin Delaney, founding director of Project Inform, said projects such as the Madison meeting reflect the growing role of AIDS advocates. "A few years ago, we begged to attend other people's meetings, and when we were allowed in, we were often greeted with skepticism and hostility. Now we call the meetings, and those same people are anxious to attend, usually at their own expense," Delaney cited two other recent activist-sponsored conferences that were well received: one on clinical trial design sponsored by ACT-UP Boston and one on vaccines sponsored by New York's Gay Men's Health Crisis.

The think-tank model is highly suitable for collaborations between scientists and activists, Delaney said. "We want them to buy into a project that they are creating, as opposed to some suggestions that are being made to them." Gebbie also praised the model: "I think there are lots of places in our HIV-related programs where we can apply this kind of gathering."

Dr. Fauci, however, was less enthusiastic. He said the Madison meeting offered nothing new scientifically, and was useful only "in clarifying perceptions about what is being done" for people "who hadn't heard parts of the story before."

Delaney is optimistic, nonetheless, that the effort's ultimate impact on research progress will be significant. "Our challenge now is keeping our nose to the grindstone so that we can reach a consensus on programmatic proposals we can present to the administration."

**Future Directions in AIDS Research
Boston, Nov. 21-23, 1993**

Moisés Agosto
National Minority AIDS Council

David Barr
Gay Mens Health Crisis

David W. Barry
Burroughs-Wellcome

Dani Bolognesi
Duke University Medical Center

Irvin Chen
ULCA AIDS Institute

Ellen C. Cooper
AmFAR

Lynda Dee
AIDS Action Baltimore

Thomas G. Dunlap
DIFFA

Anthony Fauci
NIAID, National Institutes of Health

Brenda R. Freiberg

Kristine Gebbie
Office of the National AIDS Policy Coordinator

Greg Haas
Committee of 10,000

Robert Hattoy
Department of the Interior

Martin Hirsch
Infectious Diseases, Massachusetts General

Daniel F. Hoth
Cell Genesys, Inc.

John K. Killen
NIAID, NIH

Rosemary Kuropat
DIFFA

Jeffrey Laurence
AMFAR

David Baltimore
Rockefeller University

Andrew Barrer
Office of the National AIDS Policy Coordinator

Terry Beswick
Human Rights Campaign Fund

Laurence Brown, Jr.
Harlem Hospital at Columbia University

Tom Coates
Center for AIDS Prevention Studies

Dan Cusick
ACTUP/Golden Gate

Martin Delaney
Project Inform

Max Essex
Harvard School of Public Health

Patsy Fleming
Office of the Sec., Health and Human Services

Robert Gallo
National Institutes of Health

Gregg Gonsalves
Treatment Action Group

Mark Harrington
Treatment Action Group

Maurice Hilleman
Merck Institute for Therapeutic Research

Derek Hodel
AIDS Action Council

David Kessler
Federal Drug Administration

Larry Kramer
Playwright/Activist

Stephen Lagakos
Harvard School of Public Health

Brenda Lein
Project Inform

Future Directions in AIDS Research
Boston, Nov. 21-23, 1993

Norman Letvin
New England Regional Primate Center/Immunology

Rodger McFarlane
Broadway Cares/Equity Fights AIDS

Steve Morin
Office of Rep. Nancy Pelosi

June E. Osborn
University of Michigan School of Public Health

David Pauza
University of Wisconsin Medical School

Robert Schooley
University of Colorado Health Sciences Center

Timothy M. Westmoreland
Subcommittee on Health and the Environment

Randolph F. Wykoff
Office of AIDS and Special Health Issues

Richard Marlink
Harvard AIDS Institute

Mark Milano
Act Up New York

John F. Niblack
Pfizer, Inc.

David Pauza
University of Wisconsin Medical School

George Pavlakis
NCI-Frederick Cancer Research Facility

Harold Varmus
National Institutes of Health

Flossie Wong-Staal
University of California, San Diego

Robert Yarchoan
NCI, National Institutes of Health

TREATMENTISSUES

THE GAY MEN'S HEALTH CRISIS NEWSLETTER OF EXPERIMENTAL AIDS THERAPIES

12122

November 26, 1993

Dear Subscriber:

We are writing to let you know that your Subscription to *Treatment Issues* will be up for renewal one month from the date of this letter. It is important that we hear from you should you wish to Renew or Cancel your subscription.

Your contribution makes it possible for us to continue to publish *Treatment Issues* and provide life sustaining information to people around the world. We sincerely thank you for your continued support.

If you are unable to make a contribution at this time, we will keep you on our mailing list free of charge. Please mark the box requesting a complimentary subscription.

Please mark the appropriate Box: (Please make your check payable to GMHC, Checks in U.S. Dollars ONLY)

- ☐ \$30 Individuals ☒ \$50 M.D.s/Institutions ☐ \$60 International
- ☐ Sliding Scale PWA/HIV + Low Income \$ _____
- ☒ Unable to contribute at this time, request complementary subscription.
- ☐ Please CANCEL my subscription to *Treatment Issues*.
Please comment on the back of this letter.

Mail responses to:

Attn: Paul D. Warren
GMHC, Medical Information, 2nd Fl.
129 West 20th Street
New York, NY 10011

Sincerely,

Paul Warren
Assistant Coordinator of Medical Information

Important Note: Please enclose your mailing label or write your ID# on this letter. This label has your subscription Identification number on it.

012

Bay Area HIV Advocacy Network Legislative Directory

This directory of federal and state elected officials and registrars of voters is provided to help you to contact your elected officials about bills which concern you, and funding for HIV programs. We suggest that you keep it, copy it for others, and post it in a prominent location. We will keep you informed through BAHAN and the SFAF bulletin, "HIV Policy Watch", about particular issues and the status of bills for which legislators should be contacted. If you have any comments or questions about the directory or legislative actions to be taken, or would like to join BAHAN, please call Ryan Clary, BAHAN Assistant, at (415) 864-5855 x 3032.

Registrars of voters :

Call the number for the county you live in to find out your state and federal district numbers (all hours 8-5 Monday through Friday, except as noted).

San Francisco	(415) 554-4375	8:30-4:30 M-F
Alameda	(510) 272-6973	8:30-4:30 M-F
Contra Costa	(510) 646-4166	
Marin	(415) 499-6456	8:30-4:30 M-F
Monterey	(408) 647-7621	
Napa	(707) 253-4321	
San Mateo	(415) 312-5222	
Santa Clara	(408) 299-8302	
Santa Cruz	(408) 454-2060	
Solano	(707) 421-6675	
Sonoma	(707) 527-1800	

Federal :

U.S. President :

President William J. Clinton
The White House
1600 Pennsylvania Avenue, N.W.
Washington, D.C. 20500
phone: (202) 456-1111
fax : (202) 456-2461

U.S Senate :

The Honorable _____, U.S. Senate, Washington, D.C. 20510

Barbara Boxer (D) phone : 202/224-3553 or 415/403-0100
Diane Feinstein (D) phone : 202/224-3841 or 415/249-4777

U.S House of Representatives :

The Honorable _____,
U.S. House of Representatives, Washington, D.C. 20515

Dist. #	Member	Phone
	line 2: Bay Area Counties in District	District #
1	Dan Hamburg (D) Napa Co., parts of Solano & Sonoma Co.	202/225-3311 707/254-8508
3	Vic Fazio (D) Part of Solano Co.	202/225-5716 916/666-5521
6	Lynn Woolsey (D) Marin Co., Southern Sonoma Co.	202/225-5161 707/795-1462
7	George Miller (D) Parts of Contra Costa & Solano Co.	202/225-2095 510/602-1880
8	Nancy Pelosi (D) Part of San Francisco Co.	202/225-4965 415/556-4862
9	Ronald V. Dellums (D) Part of Alameda Co.	202/225-2661 510/763-0370
10	Bill Baker (R) Parts of Alameda & Contra Cost Co.	202/225-1880 510/932-8899
12	Tom Lantos (D) Parts of San Francisco & San Mateo Co.	202/225-3531 415/342-0300
13	Fortney Pete Stark (D) Part of Alameda Co.	202/225-5065 510/247-1388
14	Anna Eshoo (D) Parts of Santa Clara & San Mateo Co.	202/225-8104 415/323-2984
15	Norman Mineta (D) Parts of Santa Clara & Santa Cruz Co.	202/225-2631 408/984-6045
16	Don Edwards (D) Part of Santa Clara Co.	202/225-3072 408/345-1711
17	Sam Farr (D) Monterey Co. & part of Santa Cruz Co.	202/225-2861 408/649-3555

- see state elected officials on reverse -

Bay Area HIV Advocacy Network Legislative Directory continued

State :

California Governor :

The Honorable Pete Wilson
Office of the Governor, State of California
Sacramento, CA 95814
phone: (916) 445-2841 fax : (916) 445-4633

California State Legislature :

The Honorable _____, State Capitol, Room _____
Sacramento, CA 95814

California State Senate :

Dist. #	Member	Room	Phone
	line 2: Bay Area Counties in District		District #
2	Mike Thompson (D) Sonoma Co.	3056	916/445-3375 707/576-2771
3	Milton Marks (D) Marin Co., parts of Sonoma & SF Co.	5035	916/445-1412 415/479-6612
4	Maurice Johannessen Napa & parts of Solano and Sonoma	4082	916/445-3353 916/224-4706
7	Daniel Boatwright (D) Parts of Contra Costa & Alameda Co.	3086	916/445-6083 510/689-1973
8	Quentin L. Kopp (I) Parts of SF & San Mateo Co.(SSF)	2057	916/445-0503 415/952-5666
9	Nicholas C. Petris (D) Parts of Alameda & Contra Costa Co.	5080	916/445-6577 510/286-1333
10	Bill Lockyer (D) Part of Alameda Co.	2032	916/445-6671 510/582-8800
11	Tom Campbell Parts of San Mateo & Santa Clara Co.	4090	916/445-6747 415/949-5401
12	Dan McCorquodale (D) Part of Santa Clara Co.	4032	916/445-3104 209/576-6231
13	Alfred E. Alquist (D) Part of Santa Clara Co.	5100	916/445-9740 408/286-8318
15	Henry J. Mello (D) Monterey Co, parts of Santa Clara and Santa Cruz Co.	5180	916/445-5843 408/373-0773

California State Assembly :

Dist. #	Member	Room	Phone
	line 2: Bay Area Counties in District		District #
1	Dan Hauser (D) Part of Sonoma Co.	2003	916/445-8360 707/576-2526

California State Assembly cont. :

6	Vivien Bronshvag (D) Marin Co., part of Sonoma Co.	4144	916/445-7783 415/479-4920
7	Valerie Brown (D) Napa Co., parts of Sonoma & Solano Co	2130	916/445-8492 707/546-4500
8	Thomas N. Hannigan (D) Part of Solano Co.	3104	916/445-8368 707/429-2383
11	Robert Campbell (D) Part of Contra Costa Co.	2163	916/445-7890 510/372-7990
12	John L. Burton (D) Parts of SF & San Mateo Co.	3152	916/445-8253 415/557-2253
13	Willie Brown Jr. (D) Part of SF Co.	219	916/445-8077 415/557-0784
14	Tom Bates (D) Parts of Alameda & Contra Costa Co.	446	916/445-7554 510/428-1423
15	Richard K. Rainey (D) Parts of Alameda & Contra Costa Co.	4015	916/445-6161 510/933-9196
16	Barbara Lee (D) Part of Alameda Co.	2179	916/445-7442 510/286-0339
18	Johan Klehs (D) Part of Alameda Co.	2013	916/445-8160 510/352-2673
19	Jackie Speier (D) Part of San Mateo Co.	4140	916/445-8020 415/871-4100
20	Delaine Eastin (D) Parts of Alameda & Santa Clara Co.	3013	916/445-7874 510/791-2151
21	Byron D. Sher (D) Parts of San Mateo & Santa Clara Co.	2136	916/445-7632 415/364-2080
22	John Vasconcellos (D) Part of Santa Clara Co.	6026	916/445-4253 408/288-7515
23	Dominic L. Cortese (D) Part of Santa Clara Co.	6031	916/445-8243 408/269-6500
24	Chuck Quackenbush (R) Part of Santa Clara Co.	2111	916-445-8305 408/369-8170
27	Bruce McPherson Parts of Santa Cruz & Monterey Co.	6017	916/445-8496 408/425-1503
28	Rusty Areias (D) Parts of Monterey, Santa Clara & Santa Cruz Co.	5136	916/445-7380 408/422-4344

AIDS Drug Assistance Program (ADAP) Information

The ADAP currently provides 14 drugs:

clindamycin	clotrimazole	dapsone
didanosine	fluconazole	gancyclovir
ketoconazole	nystatin	pentamidine
pyrimethamine	sulfadiazine	bactrim/septra
zidovudine(AZT)	ddc	

An additional 12 drugs will become available this spring:

foscarnet	pentamidine (I.V.)	amphotericin
amphotericin&5FC	acyclovir	rifabutin
paromomycin	clarithromycin	azithromycin
atovaquone	ethambutol	clofazimine



SAN FRANCISCO AIDS FOUNDATION

P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

December 10, 1993

Dear Friend.

On behalf of the Public Policy Department, we are pleased to send you the first issue of *HIV Policy Watch*, our new monthly update of policy and legislative activity.

We decided to produce this bulletin to relay important information in a more consolidated and timely manner. In each issue, you will find news and summaries of HIV/AIDS legislation and the federal and state budget, and action alerts to respond to such activity. We will also keep you informed of upcoming meetings that may be of interest.

We welcome your questions, comments, and suggestions. Please direct them to Ryan Clary, editor of *HIV Policy Watch*, at (415) 864-5855, x3032.

If you do not wish to receive the monthly bulletin, or if your agency is receiving multiple copies, please let Ryan know so we can keep our production costs to a minimum.

We hope you find *HIV Policy Watch* a helpful resource in your involvement with HIV policy advocacy.

Sincerely,

Regina Aragón
Deputy Director for Public Policy

Ryan Clary
Editor, *HIV Policy Watch*

25 VAN NESS AVENUE, SUITE 660 / 1170 MARKET STREET, 5TH FLOOR
SAN FRANCISCO, CALIFORNIA 94102
(415) 864-5855

The MAYOR'S WAR on the POOR is a WAR on People with AIDS.

FACT: Under the MAYOR'S "Matrix" Program, the SFPD has been harassing and arresting homeless people every day. 30-40 % of these people have AIDS!!

FACT: The MAYOR'S Prop. V (on the November ballot) will require welfare (G.A.) recipients, including thousands of PWA's to be fingerprinted. Further, G.A. benefits will be cut off for 45 days if the recipients are late for street sweeping assignments, even if it's due to illness, including **AIDS!!**

NOW COME ON!!

Harassing, Incarcerating, and Starving people with AIDS is **MURDER!!**

- **STOP the WAR on the poor/people with AIDS!!**
- **Vote NO on Proposition V!!**
- **Real solutions to homelessness and AIDS!!**
- **Progressive revenue options NOW!!**

CALL MAYOR JORDAN @ 554-6141
BOARD of SUPERVISORS @ 554-5184
JEAN HARRIS @ 554-6154

SILENCE=DEATH

ACT UP
GOLDEN GATE

FOR MORE INFO CALL: ACTUP/GOLDEN GATE 252-9200
NO ON V CAMPAIGN 346-3740

Get Downtown to Pay its Fair Share

The Save Our City Coalition is supporting the following progressive revenue ideas to preserve City services.

REVENUE SOURCE	Description	Revenue
Business tax	1- Raise payroll tax rate from 1.5% to 2% for companies with payroll over \$6.6 million a year (about 200 companies), with a corresponding increase in the gross receipts rate. 2- Lower payroll tax rate from 1.5% to 1% for small businesses with payroll under \$333,333 (about 2,450 companies), with a corresponding decrease in the gross receipts rate. Retain the exemption for small businesses with payroll under \$166,666. 3- Raise the gross receipts tax rate for utility companies from the lowest rate (.123%) to the highest rate (.3%).	\$20 million (\$3 million) ?
Hotel tax	Raise the hotel tax rate from 11% to 12.5%, the same rate as in Los Angeles.	\$10.7 million
Real estate transfer tax	Increase the real estate transfer tax rate from .5% to 1.5% on properties sold for \$1 million or more. (Oakland's rate for all properties is 1.5%.)	?
Transit assessment district for downtown property owners	Create a downtown transit assessment district, and assess downtown property owners for their share of the Municipal Railway deficit.	\$54 million
Stock exchange transfer tax	Establish a .1% tax on the privilege of buying and selling stocks on the floor of the Pacific Stock Exchange.	\$27.9 million
Income license fee on income over \$100,000 a year	Establish a 1% license fee for the privilege of earning over \$100,000 a year in wages, interest, rent, dividends and capital gains in San Francisco. The bulk of this fee would be paid by people who live outside of San Francisco. The \$100,000 limit would apply to individuals, not to combined family income.	\$4 million (wages) ? (interest, rent, dividends, capital gains)
Fire suppression assessment district	Create a city-wide assessment district, and assess property owners for their share of fire suppression costs. Owners of larger properties, such as highrise office buildings or commercial and industrial structures, would pay a proportionately larger amount than homeowners. No "pass-through" of this assessment to tenants.	\$35-70 million
PG&E franchise fee	Initiate legal action to renegotiate PG&E's franchise fee, which was set by "perpetual" contract in 1939. Increase the rate to 2% from the current .5% for electricity and 1% for gas. No "pass-through" to rate-payers.	\$7.7 million
Close loopholes for downtown & business	No more One Market Plaza fiascos. Fight efforts by downtown highrise owners to reduce their property tax assessments. Audit current tax collection procedures.	?
TOTAL REVENUE.....		\$156.3 - 191.3 million plus ?

Call the Mayor and Board of Supervisors today to support these measures!



ActionAlert

*For More Information Contact:
Karen Ringen, 202-986-1300 ext 16.*

September 16, 1993

Dear Colleague:

Both the Senate and House appropriations committees that determine most of the federal AIDS funding have now met, and within the next month will have to work out the differences in their bills in conference committee. As you can see from the chart (on reverse), the Senate funding was \$10 million more than the House for the Ryan White Care Act. (CDC Prevention money and NIH research dollars were the same.) The AIDS Housing Opportunities Act also fared better in the Senate, with a \$31 million increase over the House.

Both bills still have to go to the Senate floor. ***Please call or write your Senators within the next ten days and ask them to vote for the Labor/HHS and VA/HUD appropriations bills without amendments.***

When the Labor/HHS bill goes to the floor, there are often attempts to attach negative HIV amendments (i.e. restrict federal funds for condoms, needle exchange programs, etc.) Please ask your Senators to vote against such attempts, and let them know that you would like to become a resource to Senate staff should negative amendments be offered.

Sample Letter

Senator _____
U.S. Senate
Washington, DC 20510

Dear Senator:

I am writing to ask that you support the increases in AIDS funding for the Department of Health and Human Services in the Labor/HHS appropriations bill and the increases for AIDS Housing in the VA/HUD appropriations bill when both bills come to the Senate floor. In addition, I request that you vote for both bills without amendments.

In past years there have been attempts to attach negative HIV legislation to the appropriations bills. We ask that you vote against such attempts and vote for the bill in its current form. Please feel free to contact my office (*provide your phone number*) if you have any HIV related questions.

Sincerely,

(If you would rather call, the Senate switchboard number is: 202-224-3121.)

FEDERAL AIDS PROGRAMS FY 94 FUNDING SUMMARY

(Numbers are rounded to the nearest million.)

HIV/AIDS-SPECIFIC PROGRAMS	FY 93 FUNDING	FY 94 President's Budget Request <i>(increase over FY 93)</i>	FY 94 House Numbers <i>(increase over FY 93)</i>	FY 94 Senate Numbers <i>(increase over FY 93)</i>	FINAL FY 94 NUMBERS <i>(To be determined)</i>
NIH-Research	\$1.073 billion	+ \$227 million	+ \$227 million	+ \$227 million	
CDC-Prevention	\$498 million	+ \$45 million	+ \$45 million	+ \$45 million	
Ryan White CARE Act: totals	\$348 million	+ \$310 million	+ \$203 million	+ \$213 million	
<i>Title I</i>	<i>\$185 million</i>	+ <i>\$151 million</i>	+ \$133 million	+ \$143 million	
Title II	\$115 million	+ <i>\$119 million</i>	+ \$69 million	+ \$69 million	
Title IIIB	\$48 million	+ <i>\$34 million</i>	+ \$0	+ \$0	
Title IV	\$0	+ <i>\$6 million</i>	+ \$22 million* (\$1 million net)	+ \$22 million*	
AIDS Housing Opportunities Act (AHOA)	\$100 million	+ \$3 million	+ \$25 million	+ \$56 million	

* \$21 million from the Pediatric AIDS Demonstration Programs was transferred into Title IV, thus the real funding increase was only \$1 million.

MEMORANDUM



TO: AIDS Action Network

FROM: Christine Lubinski
Deputy Executive Director for Programs

RE: Health Care Reform

DATE: September 16, 1993

On Wednesday, September 22, President Clinton will announce his long-awaited proposal for health care reform. Few national initiatives in the life of the AIDS epidemic have had as much meaning for people living with HIV/AIDS. It will be imperative that every infected and affected person take this reform initiative to heart--study it, critique it, and advocate for meeting the needs of our communities.

We have reviewed the draft plan and have a number of preliminary observations:

- We welcome President Clinton's initiative. Health care reform is essential to enriching and prolonging the lives of people with HIV/AIDS. And if the plan works for people with HIV/AIDS, it will work for millions of others with chronic illnesses.
- We are especially pleased that the proposed plan offers a comprehensive benefits package that includes coverage of prescription drugs, a new initiative on community-based and home care and recognition of the need to maintain programs like the Ryan White CARE Act which will provide special services in support of those offered by the new plan.
- We are concerned about the delayed phase-in of substance abuse coverage and the lack of clearly defined confidentiality protections for a newly centralized medical records system to ensure protection of persons with HIV from discrimination and unnecessary invasion of privacy.

Accordingly, AIDS Action will devote an increasing portion of its efforts to fighting for the enactment of a comprehensive plan. We hope that you will encourage members of your organizations to do the same. Only through a national, united effort by the AIDS community will the final plan be responsive to our needs. Enclosed is the first in a series of mailings we will send you in upcoming months explaining various aspects of health care reform. This packet includes an initial set of questions and answers to assist you in answering any questions immediately following the release of the proposal, and a press release regarding AIDS Action's recent discussions with Ira Magaziner of the White House. We welcome any feedback you can give us on these or future materials.

1875

Connecticut Ave NW

Suite 700

Washington DC

20009

Fax 202 986 1345

Tel 202 986 1300

Clinton's Health Care Reform Package: What to Look For

The following questions can be used to assess the impact of President Clinton's proposed health care reform package on people with HIV infection and AIDS.

The Basic Benefits Package

Does the proposed plan guarantee basic benefits critical to all people with HIV disease -- including prescription drug coverage, substance abuse and mental health treatment, and home-based care?

The Clinton package will cover the most essential elements of health care such as hospitalization and physician services. But there are other benefits critical to people with HIV that may not be as comprehensive a part of the benefits package.

For example, *prescription drug coverage* is critical given the number of drugs and the unusually high cost of HIV-related drugs needed by people with HIV disease. The Clinton Plan is expected to have a prescription drug benefit, but it may have a higher copayment or separate deductible associated with it (though all individuals would have the same maximum -- \$1,500 -- in total out-of-pocket expenses). In addition, it is not clear that coverage of so-called "off-label" uses of FDA-approved drugs will be assured, even though off-label uses are often the standard of care for people with HIV.

Substance abuse is a major component of the HIV epidemic. Unless we address through treatment the underlying substance abuse epidemic, the number of people with HIV will continue to grow and those already infected will become sicker sooner. Mental health services are important to support coping with HIV disease and to provide long-term counseling and support for behavior change among those at risk for HIV. The Clinton Plan will be quite limited for both of these services in the first years. Full coverage for substance abuse is not expected until 2001. In the meantime, there is no guarantee that existing, separately funded programs will remain in tact, as these may be scaled down to pay for the limited benefits in the proposed plan.

Long-term home-based care and hospice care have become a basic component of HIV care. It has also been a major contributor to the reduction in the number and length of hospital stays among people with AIDS. Failure to include such a benefit will actually increase the cost of care for people with AIDS under a health care reform plan. The Clinton Plan is expected to contain a new long-term care program that emphasizes home and community-based care, but may have functional test restrictions for eligibility that could be problematic. Hospice care will be included in the plan.

Flexibility of states in defining plans

How much flexibility will states be given, both in defining and managing health care plans and in determining which and how existing federally funded care services programs will be continued?

State flexibility has not always been positive for people with HIV disease. For example, the Medicaid program gives states extraordinary flexibility in determining who will be covered for what benefits. This has resulted in dramatic variations in benefits from state to state for people with HIV/AIDS -- from almost no access to care even for the very poor, to relatively generous benefits. It is critical that the federal government be explicit in guaranteeing quality and consistent benefits throughout the country. And as special programs for particular diseases (categorical programs) are altered to reflect the new benefits in the health care reform package, states must not be allowed to reduce their current commitment to AIDS services in favor of other diseases. The Clinton plan gives states a great deal of flexibility in determining the structure and administration of the health plan; however, the benefits package and other guarantees are set by the federal government and should be uniform across the nation.

How quickly will people with no insurance be brought into the system?

Approximately 30 percent of people with AIDS have no health insurance or Medicaid coverage. Reform will be meaningless to a third of people with AIDS if they are not brought covered by the new health care plans as quickly as possible. The Clinton Plan will give states set timelines (about two years from passage) by which they must have their reform plans in place and be required to cover almost

all individuals in the jurisdiction. The most notable exceptions are undocumented foreigners and the incarcerated.

How quickly will people on Medicaid be brought into the plan? Will additional services now available to Medicaid patients be continued?

Forty percent of people with AIDS are on Medicaid, and that portion is growing. Coverage under Medicaid varies dramatically from state to state. Many states do not meet the minimum benefits package likely to be in the Clinton proposal. These states should be required to match the federal standard rapidly. The new federal program should be seen as a floor and not a ceiling on benefits for poor people. Thus, those states that might have more generous benefits than the new federal plan, should be required to maintain them. In addition, there are many so-called "wraparound" services for Medicaid recipients -- providing additional supportive services (e.g., transportation) needed by poor people -- that should be continued to sustain the value of the health care benefits. The Clinton Plan will include all Medicaid beneficiaries who also qualify for SSI and AFDC, with the same benefits as all other participants and the same choice in health plans. While states will be required to spend the same amount of money of wraparound services, they will not be required to offer the same mix of benefits as before.

Phase-in for Medicaid/Medicare recipients and the uninsured

How long is the phase-in period for comprehensive benefits? Are there separate deductibles for some benefits? Are there significant co-payments for these benefits?

While the proposal may commit to providing these benefits, there may be a significant waiting period before they are fully incorporated into the health plan. The longer the delay, the less helpful the plan will be for people with HIV/AIDS. The Clinton Plan is pushing for very fast inclusion of the basic benefits package (about two years from passage). However, some benefits important to the HIV community, such as mental health and substance abuse coverage, will not reach parity with other benefits until 2001.

One way to reduce the cost of including these benefits would be to require more

out-of-pocket payments from the individual, either through high co-payments (a minimum payment for each prescription, for example) and/or through a separate deductible (a minimum total amount for a service that must be paid by the individual before coverage begins). Co-payments and deductibles burden those who are sickest the most. Because they are sick, they will need more prescriptions filled, for example. Thus, at a time when they are least likely to be able to afford these costs, additional financial burdens are being placed on them as they try to access life-saving therapies. The Clinton Plan will have copayments for all who are covered, even the very poor. For example, there may be a \$5 or \$10 copayment for each drug prescription filled. However, there is an overall limit of \$1,500 in out-of-pocket expenses (copayments and deductibles) for all individuals and that maximum may be lower for the poor.

Will current federally funded programs providing care services to people with HIV/AIDS be continued under the Clinton plan? If any aspect is to be phased out, because those services are covered in the health plan, will they be truly equivalent to the current system?

Some parts of the health care reform plan may extend coverage to areas now paid for under separate federal AIDS-related programs, such as the Ryan White CARE Act. However, the benefits under health care reform may not be the same. For example, the Ryan White CARE Act pays for prescription drugs for lower income individuals with HIV, without any co-payment or deductible. If the health care reform plan does cover prescription drugs, then poor people should be guaranteed that they do not need to pay a co-payment or deductible. If these existing separate programs are to be phased out, then the new benefit should be equivalent; otherwise these federal programs should remain in place to make up the difference. The Clinton Plan specifically exempts the Ryan White CARE Act from phasing out after health care reform. However, other HIV-specific programs, such as HIV prevention services, may be folded into a larger all-purpose public health (block) grant to the states for prevention. This creates the danger that states might choose to reduce funding for HIV prevention in favor of more "popular" public health programs. The plan does envision making significant increases in public health prevention funding, money for which HIV programs could compete.

Confidentiality

Will the plan guarantee confidentiality of patient records and forbid discrimination based on any information in one's record or based on the kind of care that has been accessed?

The potential centralization of record-keeping and mass computerization of patient records significantly increases the potential for violations of confidentiality. While one basis for this concern in the past has been fear of losing health insurance coverage, it is not the only one. People with HIV disease continue to face discrimination in a number of arenas -- including employment and accessing health care itself. There must be federal, legislative assurances that health care records generated by this new plan cannot be used directly or indirectly to discriminate. The Clinton Plan is vague about new legislation in this area. It suggests that the new National Health Board running the program will set confidentiality standards, but if these are not set before the plans are implemented, it may be too late. New federal confidentiality standards must set a bottom line of protection for privacy and against discrimination for people with HIV disease in health care, employment, housing, family law, and other areas.

Regulations governing employer opt-out/self-insured plans

Will pre-existing conditions protections and minimum benefits standards apply to all self-insured programs?

Self-insured plans (under which large employers pay for health care costs directly rather than through an insurance company) have been notorious in their attempts to limit HIV-related coverage. If large employers will be permitted to opt out of the current system, then they must be required to at least adhere to the minimum benefits package established and guarantee that there will not be denial of coverage for pre-existing conditions. Without a ban on allowing self-insured employers to exclude pre-existing conditions, one of the most basic principles of health insurance reform -- the ability to maintain the same coverage from job to job -- will be undermined. The Clinton Plan is clear in requiring that large corporations offer the same standard benefits package without pre-existing condition exclusions as well as a choice of plans for all employees.

Managed care provisions important to persons with HIV/AIDS

What assurances will people with HIV have that managed care systems will not want to discourage enrollment by people with costly illnesses despite any official requirements for openness?

Managed care plans have not universally welcomed people with HIV. Managed care poses a number of challenges for people with illnesses that are costly and require a special expertise. People with HIV need federal assurances that managed care plans will be required to have HIV-specific expertise readily accessible -- not just general infectious disease experts -- and without complex gatekeeping functions through case management by non-HIV experts. People with HIV also should have significant freedom to choose their physicians, even going outside a plan, to assure care by someone with appropriate cultural sensitivities -- whether it is to HIV disease per se, racial/ethnic or language background, drug dependency, or sexual orientation. Finally, the reform plan must assure that there are financial incentives for plans to enroll people with expensive diseases such as HIV.

The Clinton Plan proposes that the National Health Board establish both consumer protection and quality assurance standards, with further regulation by the states of the performance of individual plans. This must be done quickly, before plans are in place. Theoretically, everyone will have the option of a fee-for-service program, however it will be more costly to the individual because of higher co-payments and may therefore exclude many people with HIV disease. The plan does recognize that fee-for-service plans may be more appropriate for individuals with disabilities by requiring that all Medicaid beneficiaries be assured this option during the phase-in of the plan. In addition, the plan contains a fairly specific commitment to "risk adjustment" -- reimbursing plans at a higher rate when they have a disproportionate number of enrollees with special medical needs.

- Let's say you're certain you want to participate in a trial as long as the vaccine shows a real promise of working. How will you know the vaccine candidate you're helping to investigate is the best one?

Lots of potential HIV vaccines are being considered for wide-scale trials. The decision to study one will have much to do with the drug company's strategy and not necessarily with the promise of a particular vaccine candidate.

- Would you enroll in a vaccine study if it were to exclude you from later studies?

Participation in a vaccine study could restrict your entry to future trials of different vaccines and immune-based therapies.



What is a vaccine, Anyway?

A vaccine is designed to stimulate the body into creating its own protective antibody response to a particular disease. Whole inactivated virus or selected live particles (antigens) from the virus are injected (inoculated) into the body and presented to the body's immune system. A successful vaccine causes the body to produce antibodies to a virus, giving the body a defense against future exposure to that disease.

The AIDS Virus

Because HIV is one of the fastest mutating viruses known and because of the great liability risks associated with vaccine research, it is unlikely that a simple vaccine solution to the epidemic will present itself. A successful vaccine will probably require a complex series of injections spaced over a space of several months or even years. Exactly how to measure the effectiveness of an AIDS vaccine remains a highly controversial dilemma. How much evidence is enough?

Preventative HIV Vaccine Trials

Questions to Ask Yourself Before You Enroll

PROJECT INFORM

1965 Market Street
Suite 220
San Francisco CA 94103

415-558-8669

We all want to see an end to the AIDS epidemic. An effective and available HIV vaccine would be one giant step in the right direction. HIV vaccine trials are expected to enroll thousands of participants within several years in the Bay Area alone. But before we get too excited about the possibility of a vaccine, we have to decide what we want from the vaccine trials.

Ask Yourself:

- Would you enroll in a vaccine study even if you were to test positive for HIV antibodies as a result of receiving the vaccine?

If you are inoculated with one of the current candidate vaccines, you will probably become HIV positive on a standard Elisa test since you will produce antibodies to HIV. Testing HIV+ can cause discrimination from insurance companies, employers, and medical providers. It can also make entering countries with anti-HIV policies difficult or impossible.

- If you enrolled in a vaccine study, would you continue to practice safe sex?

If you participate in HIV Vaccine studies you won't know for sure if you're receiving vaccine or a placebo (nothing). In either case, there is no guarantee that you are protected against HIV. In fact, a vaccine might create an increased susceptibility to HIV infection. The need to practice safe sex remains.

- If you were sure you were receiving a vaccine but were uncertain about its effectiveness, would you still practice safe sex?

The Department of Health has claimed a 60% effective vaccine distributed immediately would save more lives than a 100% effective vaccine discovered much later. But is a less than perfect vaccine worth risking unsafe sex?

- What's in a Vaccine Trial for You?

What kind of guarantee about a vaccine's safety and your

protection against future anti-HIV discrimination will you need before you can comfortably participate?

- What about Future Access?

The discovery of a vaccine does not insure that people who need it most will be able to afford it. The Hepatitis B vaccine was discovered largely through the participation of gay men. It is not cheaply available, however, through any existing clinic, and insurance companies won't pay for it if your only risk factor is having gay sex. What's to insure that an HIV vaccine will be available once its discovered? What guarantees of future availability are necessary before you can support a trial?

- How about HIV + Friends?

Blood samples from trial participants, high in HIV antibodies, will be used in experimental treatments for children with HIV. Are you willing to accept that HIV+ adults may not benefit from these studies?

FOR IMMEDIATE RELEASE

CONTACT:

EDWARD ZOLD 415/252-9200•Fax 415/252-9277

JOHN PINGREE 510/8364401

MARK CONLAN 619/688-1886•Fax 619/2993430

**ACT UP "DAY OF THE DEAD"
POLITICAL FUNERAL/DEMONSTRATION**

On Friday, October 29 at 12:00 Noon Pete Wilson and the State Health Department will be the target of a political funeral/demonstration at the State Capitol Building in Sacramento.

The demonstration is focused on the flimsy State AIDS budget which is completely devastating the lives of people with HIV/AIDS in California. Gov. Wilson's AIDS budget for 1993-1994 is flat and does not reflect the growing AIDS case load in the state. This adds up to less care, less treatment and prevention and will certainly mean more deaths. (See enclosed State Budget)

Flat funding will effect AIDS education and prevention, alternative test sites, confidential testing, children's services, home health, adult day care, homeless shelters and the essential AIDS Drug Assistance Program. The budget will additionally demolish Mental Health AIDS counseling programs, research at University of California, AIDS treatment at State correctional facilities, and treatment for IDU's. Dramatically, Wilson's inane budget will effect assistance programs such as SSI, Medi-Cal, and AFDC, and will jeopardize crucial federal Ryan White funds.

In addition to this outrageous evasion of AIDS health care, ACT UP demands full funding for tuberculosis and other communicable diseases, state funded needle exchange, endowment of CAL OSHA, endorsement of alternative treatments, and the repeal of Proposition 13. We insist that the Governor and legislature stop their corporate coddling in order to plan for and secure future funding for all health care programs in California. And finally we call on Pete Wilson to stop his grab at local property tax revenues which has severely impacted local health care programs throughout the state.

The political funeral is the first of it's kind in Sacramento and is being organized by a newly formed coalition of California ACT UP chapters. ACT UP/Golden Gate, ACT UP/San Francisco, ACT UP/East Bay, ACT UP/Sacramento, ACT UP/San Diego, and ACT UP/Los Angeles are the participating chapters. AIDS and health care advocates are involved and endorsing this action.

Matthew Sharp from ACT UP/Golden Gate states, "It is now time to target the State AIDS budget and demand treatment, care and prevention for the overwhelming, growing AIDS case load. The powers that be must end their slashing of health budgets everywhere in order to appease the stagnant economic climate. Health care is a right for all Californians!"

ACT UP is a diverse, non-partisan group of individuals dedicated in fighting AIDS through non-violent direct action.

Political Funeral

"Bring Out Your Dead!"

In the time of the Black Plague, Town Criers urged the townspeople to bring their dead into the streets to show the enormous loss and suffering of the disease. Now ACT UP calls on the public to memorialize our dead with ashes, photographs and memorabilia, and demonstrate our grief and anger at the State.

ACT UP

**Full funding of state health care programs,
AIDS programs, including ADAP,
tuberculosis and other communicable diseases
No cuts to SSI, AFDC, Medi-Cal assistance programs
State funded needle exchange
Endorse alternative treatments
Fully fund Cal OSHA
Keep up with the growing AIDS caseload
Repeal proposition 13
Appropriate health care in the state prison system
No more corporate coddling
Stop Pete Wilsons grab of local property tax revenues**



**State Capitol Building, Sacramento
Friday Oct. 29, 12 noon**

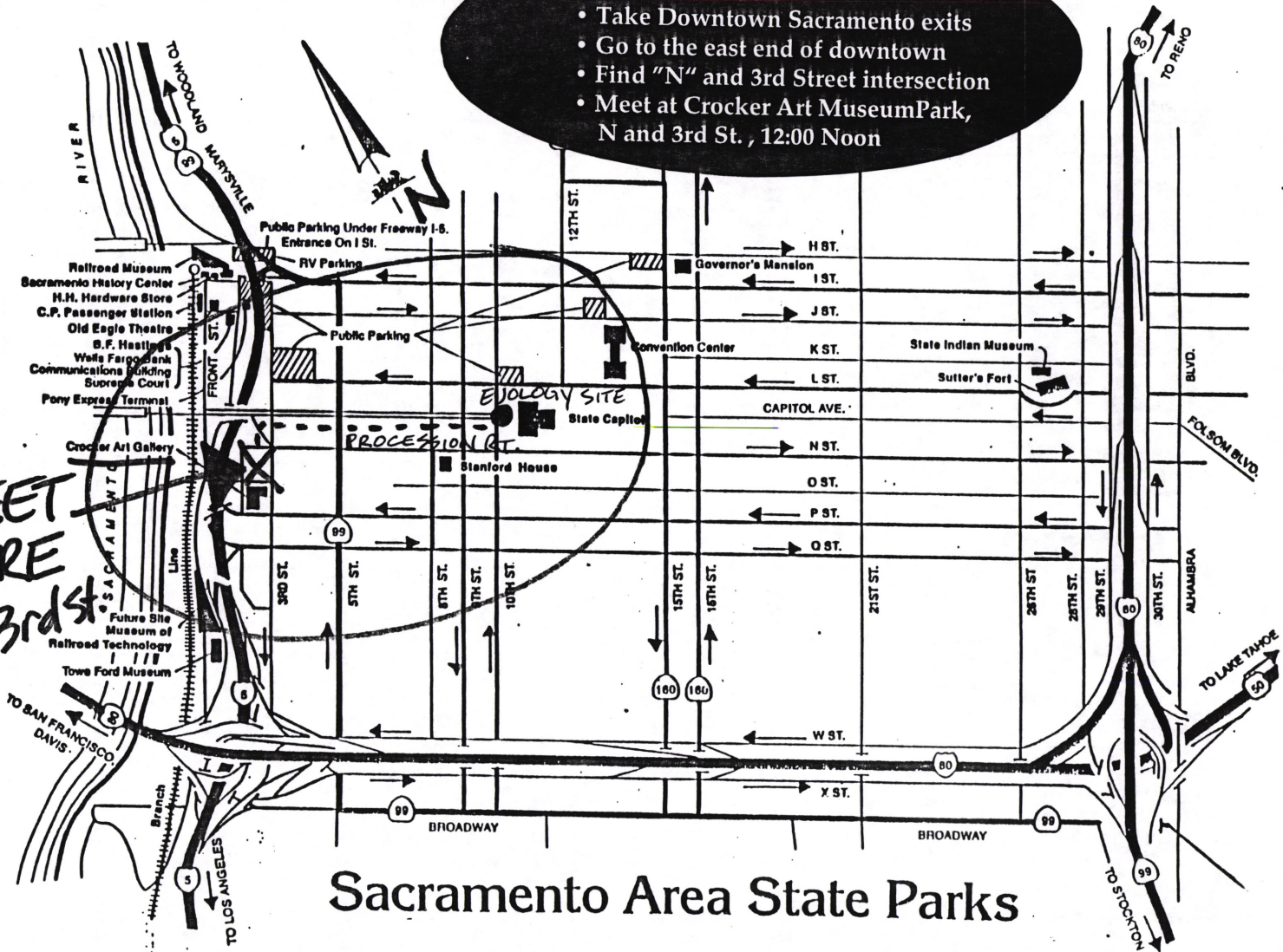
For transportation or other info CALL: 415/252•9200

State Health Budget Disaster

Political Funeral Directions

- Take Downtown Sacramento exits
- Go to the east end of downtown
- Find "N" and 3rd Street intersection
- Meet at Crocker Art Museum Park,
N and 3rd St. , 12:00 Noon

MEET
HERE
N + 3rd St.



Sacramento Area State Parks



GOVERNOR'S OFFICE

November 9, 1993

The Reverend William M. Davis
Post Office Box 422771
San Francisco, California 94102-9991

Dear Reverend Davis:

Thank you for your letter to Governor Wilson concerning the demonstration by the AIDS Coalition to Unleash Power (ACT-UP) at the State Capitol on October 29, 1993. The Governor has asked me to respond. I personally witnessed a portion of the ACT-UP demonstration, and I have made several inquiries in order to respond to the allegations made in your letter.

First of all, we sympathize deeply with your frustration over this horrendous epidemic. In your letter, you mention the loss of your best friend. We sympathize with you, and can only begin to imagine the depth of your sorrow. We can see how this march would be a healing experience of sorts for you.

In your letter, you express your unhappiness that ACT-UP was not allowed onto the Capitol grounds, and you indicate that you hold the Governor responsible. Reverend Davis, I am afraid that you have received some inaccurate information, and I would like to set the record straight.

The Legislature and not the Governor is responsible for managing the Capitol grounds, as the Capitol is a legislative building under the authority of the Legislative Branch. Thus, the Governor could not and did not order anyone barred from the grounds. Indeed, the Governor was in Southern California and not at the Capitol on the day of ACT-UP's march.

The California State Police's Office of Capitol Services (OCS) handles security at the State Capitol. OCS requires that any group wishing to reserve any part of the Capitol Park for any event must obtain a permit. There is no fee for the permit. ACT-UP refused to fill out a permit on at least two occasions for the October 29, 1993 rally. Specifically, according to OCS, ACT-UP was reluctant to complete the portion of the application listing responsible parties for any property damage. State Police advised ACT-UP that its demonstrators could be subject to arrest as an unlawful assembly without a permit.

While the state respects any citizen's constitutional rights to freedom of speech and assembly, a procedure has been established to allow for this expression while protecting the

Page Two

Capitol grounds and the safety of visitors and employees at the Capitol. In fact, OCS processes roughly 1,500 permit requests each year and will work with anyone to accommodate any event request -- as long as a permit is requested. I assure you that ACT-UP was not treated differently than any other group when State Police requested that it obtain a permit.

Quite simply, the State Police had no idea what conduct to expect from ACT-UP because the group did not have a permit. As a result, the State Police exercised routine caution and stopped ACT-UP's march at the edge of the Capitol grounds.

While you may agree or disagree with this assessment, ACT-UP does not have a reputation as an orderly group -- a reputation on which the group prides itself, and one which is reflected in the group's name. The State Police's experience with ACT-UP includes a disorderly demonstration in 1991 in which several thousand dollars of damage occurred to Capitol property.

You also state that, while ACT-UP was excluded from the Capitol grounds, a group of "Christian protestors -- counter" was escorted into the Capitol by the Governor. First, as I said, the Governor was not at the Capitol that day. Secondly, the other group holding a rally at the Capitol that day gathered to rally against Proposition 174, the school voucher initiative. This group gathered on the north side of the Capitol and had a permit from OCS to do so. In fact, another group without a permit and supporting Proposition 174 attempted to disrupt this rally. State Police stopped the disruption, and advised the second group to obtain a permit, in accordance with OCS rules, if its members ever desire to have an event and exercise their constitutional rights to freedom of speech and assembly. Neither group was a counter-demonstration to your march, as you state, and no one from this office escorted either group into the building.

I also wish to clarify the Governor's record on matters related to AIDS and HIV. Unfortunately, this record has been greatly distorted. Among other things, the ACT-UP march reportedly was organized to protest purported reductions in funding for AIDS and HIV programs by the Governor. We cannot emphasize more strongly that the opposite is true. In these difficult fiscal times in which funding for nearly every state program has suffered, the Governor has worked to protect funding for AIDS and HIV programs from reductions. For your information, a summary of the Governor's record on AIDS and HIV issues is enclosed. I urge you and your fellow ACT-UP members to review the Governor's record as Chief Executive of California and as a member of the United States Senate, as it may provide some enlightening information on the Governor's commitment to fighting this tragic disease. The Governor

Page Three

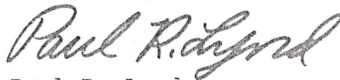
has signed long-sought state legislation requiring AIDS prevention instruction in schools (Assembly Bill 11) and banning discrimination in employment and housing against Californians with AIDS or HIV infection (Assembly Bill 1286).

Recently, the Governor signed additional legislation to help the fight against AIDS and HIV. Assembly Bill 1100, the Health Insurance and Equity Act, will guarantee that Californians with AIDS or HIV infection receive the medical care they need and are not abandoned by health insurers. Among other things, AB 1100 prohibits "post claim underwriting," in which an insurance carrier denies a claim based on information not provided or requested during the original underwriting process. The Governor also signed Assembly Bill 925 to establish a check-off on state income tax forms to help fund AIDS and HIV research efforts.

Reverend Davis, one additional point should be clarified. You state that you will continue "to fight for equal justice and equal rights for my gay, lesbian, and bisexual brothers and sisters." Despite whatever you may think, the Governor always has opposed discrimination. He signed Assembly Bill 2601 to prohibit discrimination in employment on the basis of sexual orientation. The Labor Commissioner is making a dedicated effort to enforce this law and protect these employee rights, and she has issued several decisions ordering remedies for victims of discrimination.

Sadly, we all know the sorrow, frustration, and tragedy of fighting a disease with no known cure. The Governor has been and remains committed to persevering in our fight against AIDS and HIV. You may be assured that the Governor will continue to work with officials at the state and national levels to promote expanded health care, support, and prevention services for AIDS and HIV. We will ensure that California remains at the forefront in the ongoing fight against this insidious disease.

Sincerely,

A handwritten signature in dark ink, reading "Paul R. Lynd". The signature is fluid and cursive, with the first name "Paul" being more prominent and the last name "Lynd" following in a similar style.

Paul R. Lynd
Constituent Affairs Representative
For Health and Welfare

Enclosures



11/29/93

Dear Friends:

Thank you for your participation in "Bring out Your Dead." All of our hard work provided a truly powerful and moving event. Enclosed you will find an itemized expense report and a packet of receipts for expenses incurred by ACT UP/ Golden Gate members. At this time, we are asking for funds to cover some expenses. The total cost is divided evenly among participating chapters, as we discussed on the conference calls.

We are certainly aware that some chapters operate on a very small budget. If you are unable to pay the full amount that we are requesting, any amount that you are able to contribute towards these costs would be greatly appreciated.

Feel free to contact Edward Zold or Matthew Sharp @ 415/252-9200 with any questions on this issue.

Thanks again for a great action!

Sincerely,

Handwritten signatures of Edward Zold and Matthew Sharp in cursive script.

Edward Zold

Matthew Sharp

ACT UP/Golden Gate Lobby Day Fact Sheet

Budget:

- Budget issues at the state level continue to plague us. The basic thorns are Pete Wilson, the recession, and certain legislators who have always been difficult or willing to consider AIDS a priority. Last year and the previous five years the AIDS budget in the state of California has been *flat* meaning that no new monies were allocated for AIDS except for some new TB programs and funds for a Women's Health Initiative(prevention). Wilson continues to cut money from Medi-cal and AFDC, which leaves a greater burden on counties.
- The AIDS Budget Coalition (a state wide coalition of service providers and advocates) is proposing a budget augmentation of \$5 million which would mean \$3 M for prevention and education and \$2 M for counseling and testing. These are the two most seriously underfunded programs according to ABC. Even though this augmentation would not restore the programs to their needed level at least it's something. ACT UP/Golden Gate has always demanded that *all* funding be restored to match inflation and the growing AIDS caseload.(and god forbid a plan for the future)
- Wilson is relying on three billion dollars from the fed to beef up his budget. Most experts agree, especially with the LA earthquake, that this money will never materialize.
- The state fiscal year begins July 1, 1994. Hearings will be held in the Assembly Health Subcommittee on April 20 hence the choice of our April 18th lobby day. SFAF AIDS Lobby Day will be held May 16 and legislators will need continued pressure through the summer until the budget reaches Gov. Wilson.
- Another important issue related to the AIDS budget is ADAP. The ADAP has been expanded, however how is the program being advertised? What are plans for adding vitamins and minerals? What about accountability?
- Legislators to target for budget issues:
Assembly—John Vasconcellos, Paul Horcher, John Burton, Barbara Friedman
Senate—Alquist, Tim Leslie, Mike Thompson

New Bad Legislation:

- A slew of dangerous, punitive HIV/AIDS reporting and testing legislation is in different stages of development in the California legislature. Over the epidemic years this is one area in which we thought we'd licked the problem. However, due to right-wing fundamentalist efforts and an increasingly conservative California Medical Association, this scary legislation is appearing once again. In the past we have always seen a few testing bills introduced, but never this many in one year and more bills increases the odds that some of them may pass.

- This legislation will cost the state *millions* for nothing. We also know that it could jeopardize federal CDC prevention dollars. Appropriate testing bills already exist that aren't as punitive. Additionally, we know that testing someone that is accused still doesn't tell us if the victim has been exposed. Isn't that the bottom line?
- The most appalling bill is the Rogers Bill **SB1432** which because it wants to re-define venereal disease to include HIV/AIDS, would incorporate existing Health Codes including quarantine. In a recent community meeting with Willy Brown the bill is supposed to die in committee, however since it has such dangerous implications, we need to lobby against it.
- The Russell Bill **SB 1239** is probably the furthest along. It would require non-consensual testing of a patient if there was a "significant exposure" according to a doctor or health care worker. The bill has passed the Senate and is in Assembly Health Cmte.
- Other testing bills are:
 The Leslie Bill **SB 1864** mandates HIV testing of people who bite, scratch, or otherwise exchange body fluids with an employee of a school or community college.
 Bergeson Bill **SB 2025** which would require each prison in the Corrections system to investigate, and ascertain all reported or suspected cases of any communicable disease.
 Martinez **AB 109X** and Conroy **ABX 56** would expand current legislation to involuntarily test defendant or other people not named in the criminal complaint.
 Boland **AB 2815** would mandate testing for persons convicted of certain sex crimes to include lewd and lascivious acts upon a child.
 Honeycutt **AB 3003** would mandate testing for people convicted of child molestation or sexual offenses on a minor under 18.
 Knight **AB 3207** re-defines venereal disease to include HIV/AIDS.
- These testing bills all further discriminate against people with AIDS, will make having HIV/AIDS a crime; will not help people make health care decisions; are completely cost prohibitive for a state that is financially strapped; are oppressive to all people with communicable diseases; and they take our education efforts back to where we started.
- Legislators to target:
 Assembly—Bob Eppler, Paula Boland, Kathleen Honeycutt, Mike Gotch, Tom Umberg, Pete Knight
 Senate—Dianne Watson, Tim Leslie, Bill Lockyer, Nick Petris, Dave Roberti

We also need to lobby for a number of good bills that are summarized on the Life Lobby Legislative Update 3/17/94.

—Matthew Sharp

MEMORANDUM

TO: ALL INTERESTED PERSONS

FROM: Edward Zold
ACT UP/ Golden Gate

DATE: 14 April 1994

RE: CDC

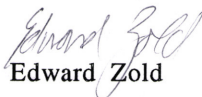
Please review the copy of this letter to Lydia Ogden (CDC, HIV/AIDS Division). The ACT UP/ Golden Gate Prevention Committee has discovered many serious problems with CDC's Prevention Marketing Initiative (PMI). These problems include the absence of messages specifically for gay, lesbian and bisexual youth, the failure of CDC to communicate with it's own advisors, and the failure of CDC to seek meaningful community input in the development of large and costly prevention initiatives.

If you share any of the concerns mentioned in this letter, please contact Lydia Ogden at (404) 639 0956 and Dr. James Curran at (404) 639 0600.

We will continue to monitor CDC's efforts on these fronts and keep you abreast of any new developments.

Please contact me at (415) 252-8956 with any questions.

Thank you for your time and interest.


Edward Zold

Taking The Street

Photos 1989-1993

Jane Philomen Cleland



puamp3

Josie's Juice Joint

October 1st thru October 31st

3583 16th Street 415-861-7933

Opening Party Sunday October 10th 4pm-6pm

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