

MINUTES OF FIRST MEETING
OF BOARD OF DIRECTORS OF
NATIONAL AIDS RESEARCH FOUNDATION

AUGUST 14, 1985

A meeting of the Board of Directors of the National Aids Research Foundation, a California corporation, was held at the home of Christopher Hersey, 704 North Arden Drive, Beverly Hills, California on August 14, 1985 at the hour of 7:30 p.m.

DIRECTORS PRESENT:

The following directors were present:

1 Michael S. Gottlieb,	10 B. Decker
2 Christopher Hersey,	11 C. Kivovitz ✓
3 Arnold Klein,	12 D. SANDERS ?
4 Charles Larson,	13 S. Andelson
5 William Misenhimer,	
6 Michael Roth,	14 MK
7 Rand Schrader,	15 BJS
8 Peter Scott,	16 TB
9 Joel Weisman, and	
Robert Winters	

Not in attendance were Sheldon Andelson and David Sanders.

FILING OF ARTICLES:

Charles Larson announced that the original Articles of Incorporation of the corporation had been filed in the Los Angeles Office of the Secretary of State of California on August 2, 1985. He also reported that a Certificate of First Amendment of the Articles adding the word "National" to the name had been submitted to the Secretary of State but not yet filed.

APPLICATIONS FOR TAX EXEMPT STATUS AND FOR EMPLOYER IDENTIFICATION NUMBER:

Charles Larson also reported that Applications for Tax Exempt Status had been filed with the Internal Revenue Service and with the Franchise Tax Board and that an Application for Employer Identification Number had been submitted with the Internal Revenue Service.

SCIENTIFIC ADVISORY COMMITTEE:

The directors discussed the need for a Scientific Advisory Committee to evaluate grant applications. Michael Gottlieb purported

that he had contacted Drs. James Curran, Paul Volperty and Martin Hirsch and that they had all expressed an active desire to be on such a committee. The directors expressed their appreciation to Dr. Gottlieb for the prominent physicians he had enlisted and, upon motion duly made, seconded and unanimously carried, the following resolution was adopted:

RESOLVED, that Michael Gottlieb be the Chairman of a Scientific Advisory Committee whose duties will include the preparation of a grant application process, and the evaluation of grant applications and that he continue to recruit other volunteers to be recommended to the directors as members of the Committee.

RELATIONSHIP WITH AIDS MEDICAL FOUNDATION:

Michael Gottlieb discussed his meeting in New York City with Dr. Mathilde Krim and Terry Burne, President and Executive Director respectively of the Aids Medical Foundation. The discussion ensued about the advantages and disadvantages of a combined effort with this group, by merger or otherwise. Upon motion duly made, seconded and unanimously carried, the following resolution was adopted:

RESOLVED, that Dr. Mathilde Krim be invited to Los Angeles in two weeks to continue discussion and negotiations with respect to this matter.

NAME OF ORGANIZATION:

Peter Scott asked for a definition of the word "research" in the name of the organization, National Aids Research Foundation. He questioned in particular if the word research included education. It was felt by some members that it was important to include the word research in the name to appeal to the widest spectrum of support. Others felt that the term "research" might limit the scope of the organization downstream and that a more encompassing name would be National Aids Foundation. There was no resolution of this matter.

NEWSLETTER:

Arnold Klein suggested that we have a newsletter for prompt dissemination of information. This suggestion was greeted favorably although no specific plans for a newsletter were made.

NATIONAL REPRESENTATION ON BOARD OF DIRECTORS:

There was a discussion about the national scope of the organization. Although the organization is beginning in Los Angeles, the directors agreed that it was important to bring in

representatives from other areas such as New York, San Francisco and Texas. It was agreed to further address this issue at the next meeting.

MAILING ADDRESS:

It was announced that we now have an official mailing address which is P.O. Box 491218, Los Angeles, California 90049. It was suggested that we obtain a lock box at a bank to which contributions could be mailed directly.

BANK ACCOUNTS:

It was announced that accounts were being established at Security Pacific Bank for monies donated to the foundation.

DONATION:

Michael Gottlieb and William Misenhimer related that a \$250,000 gift was being made by Mr. Rock Hudson and that he would be requesting that donations be made to the Rock Hudson Aids Research Fund which would flow to our foundation.

ACCOUNTING FIRM:

The directors discussed the need to enlist the services of a good accounting firm. The firm of Peat, Marwick and Mitchell as well as other firms were mentioned. Michael Gottlieb volunteered to look into the matter further.

LOGO:

Michael Roth announced that Michael Parish had volunteered to develop a logo for the foundation.

FUND RAISING EFFORTS:

Michael Roth related that Mark Simons was willing to present four proposals for fund raising endeavors.

ORGANIZATIONAL MATTERS:

William Misenhimer listed multiple organizational details that needed to be dealt with soon. These included bookkeeping arrangements, public relations plan, PR kits, fund raising plans, budgeting, distribution of funds plan, committee composition, job

descriptions, investment plans, accounting procedures, organizational flowcharts, hiring plans, administrative procedure personnel, granting procedure plans, social service permits, obtaining an office site, furnishings, computer, newsletter development and development of trustees, governors, etc. (including their titles), and identifying individuals to complete the organization.

APPOINTMENT OF EXECUTIVE DIRECTOR:

The discussion then turned to the position of executive director of the foundation. Various approaches for selection were detailed. It was felt that the individual hired for the position not only have excellent previously demonstrated administrative capabilities, but that the person should already have some understanding of the disease itself. Mr. Misenhimer was then asked to leave the room and a discussion ensued as to whether an offer should be made to him to appoint him as executive director. All individuals who had first hand knowledge of his abilities offered solid praise and admiration for the job that he was doing as executive director of Aids Project Los Angeles. It was duly noted that hiring him away from Aids Project Los Angeles might engender displeasure from an organization that we hope to work very closely with. Many members expressed the opinion that no better individual could be found as executive director even if a national search were undertaken and that given the need to start up quickly, upon motion duly made, seconded, and unanimously carried, the following resolution was adopted:

RESOLVED, that the position of executive director of the foundation should be offered to William Misenhimer and that a specific salary and benefit package should be worked out by a subcommittee consisting of Michael Gottlieb, Arnold Klein, Peter Scott and Joel Weisman.

PARTICIPATION BY ELIZABETH TAYLOR:

William Misenhimer announced that Elizabeth Taylor has volunteered to lead the national fund raising effort. A discussion ensued as to what her exact title should be. The directors expressed their gratitude for her commitment.

There being no further business to come before the meeting, upon motion duly made, seconded, and unanimously carried, the meeting was adjourned at 11:10 p.m.

ROBERT WINTERS, Secretary

APPROVAL OF MINUTES BY
DIRECTORS WHO WERE NOT
PRESENT:

SHELDON ANDELSON

DAVID SANDERS

MINUTES OF SPECIAL MEETING
OF BOARD OF DIRECTORS OF
NATIONAL AIDS RESEARCH FOUNDATION

AUGUST 21, 1985

A meeting of the Board of Directors of the National Aids Research Foundation was called by the President and held at the home of Christopher Hersey, 704 North Arden Drive, Beverly Hills, California, on August 21, 1985. It was called to order at 8:00 p.m. by the President, Michael Gottlieb.

DIRECTORS PRESENT:

The following, constituting all of the directors, were present:

Sheldon Andelson,
Michael Gottlieb,
Christopher Hersey,
Arnold Klein,
Charles Larson,
William Misenhimer,
Michael Roth,
David Sanders,
Rand Schrader,
Peter Scott,
Joel Weisman, and
Robert Winters

MINUTES OF MEETING OF AUGUST 14, 1985:

The minutes of the August 14, 1985 meeting of the directors were presented and upon a motion duly made, seconded and unanimously carried, it was resolved that said minutes be approved as written with the correction of the spelling of two individual's names.

APPLICATIONS FOR TAX EXEMPT STATUS AND EMPLOYER IDENTIFICATION NUMBER:

Charles Larson reported that attempts were being made to expedite these applications.

RESOLUTIONS OF THE CORPORATION:

Upon motion duly made, seconded and unanimously carried, the following organizational resolutions were adopted:

Approval of Actions By Incorporator:

RESOLVED, that the actions taken by written consent of the sole incorporator of this Corporation on August 10, 1985 and August 13, 1985, which written consents have been presented to this meeting, be, and they hereby are, in all respects approved, ratified and confirmed;

RESOLVED FURTHER, that the Secretary of this Corporation be, and he hereby is, directed to file a copy of said written consents in the Minute Book of this Corporation, preceding the minutes of this meeting.

Filing of Articles:

RESOLVED, that the Secretary insert a certified copy of the Articles of Incorporation which were filed on August 2, 1985 in the Minute Book of the Corporation along with a copy of the First Amendment thereto.

Approval of Bylaws:

RESOLVED, that the form of bylaws adopted by the sole incorporator by written consent dated August 10, 1985 be approved and ratified as the bylaws of the Corporation and that the Secretary is authorized and directed to execute a certificate as to the adoption of said bylaws and the ratification thereof by these resolutions, to affix his certificate, immediately following the last page thereof, to an original copy of said bylaws and to cause said bylaws, together with this certificate, to be placed in the Minute Book of the Corporation.

Adoption of Corporate Seal:

RESOLVED, that this Corporation adopt the corporate seal, an impression of which appears in the margin of these Minutes.

Adoption of Accounting Year:

RESOLVED, that the first accounting year of this Corporation is fixed from August 2, 1985 to December 31, 1985 and thereafter the accounting year of this Corporation is to begin on January 1 of each year.

Establishing A Depositary For Corporation Funds:

RESOLVED, that this Corporation shall establish one or more bank accounts as the officers determine is necessary and desirable.

Payment of Expenses of Corporation:

RESOLVED, that the treasurer of this Corporation be, and hereby is, authorized to pay all charges and expenses incident to or arising out of the organization of this Corporation and to reimburse the persons who have made any disbursements therefor.

Applications for Tax Exempt Status:

RESOLVED, that the Federal and California applications for tax exempt status which were signed by the President of the Corporation and filed with the Internal Revenue Service and the Franchise Tax Board on August 14, 1985 are hereby approved.

Fictitious Business Name Statement:

RESOLVED, that this Corporation file and publish a fictitious business name statement indicating that it will also be using the name ROCK HUDSON AIDS RESEARCH FUND.

BYLAW CHANGES RE: MEMBERS AND DIRECTORS:

Charles Larson reported that the bylaws provided for both "members" and "directors" of the corporation, that the same individuals presently were serving in both capacities and that since it appeared that that would always be the case, it would be administratively easier if the bylaws were amended to eliminate the concept of members. Voting both as members and as directors, upon motion duly made, seconded and unanimously carried, the following resolution was adopted:

RESOLVED, that the Bylaws of the Corporation be amended to eliminate statutory "members."

ROCK HUDSON AIDS RESEARCH FUND:

Mr. Rock Hudson and his business manager, Mr. Wally Scheft, have volunteered that any money collected in his name support research against AIDS. They have agreed that such funds could be collected under the name Rock Hudson Aids Research Fund which could be a dba of the National AIDS Research Foundation. Bill Misenhimer reported that a mailing will be commenced

to those 15,000 individuals who have sent notes and cards to Rock Hudson. The details of the mailing will be worked out by the Executive Director. All present were very appreciative of Mr. Hudson's sincere commitment to this goal.

REGIONAL AND NATIONAL DEVELOPMENTS:

Michael Gottlieb reported that the AIDS Research Foundation of America in Washington, D.C. was led by Marla Tysner. Although it has communicated with various governmental agencies, it did not appear to be a rapidly developing foundation.

The AIDS Medical Foundation in New York led by Dr. Mathilde Krim continued to express an interest in consolidating the two foundations. It was announced that Dr. Krim would be coming to Los Angeles next Monday, Tuesday, and Wednesday (August 26, 27 and 28) for further discussions about the feasibility of doing this.

SCIENTIFIC ADVISORY COMMITTEE:

In addition to the interest previously expressed by Drs. Curran, Volperding and Hirsch to be on the Scientific Committee, Dr. Gottlieb reported that Drs. Robert Golla, David Pickar and David Sanders had been contacted and expressed interest.

It is anticipated that this committee would physically meet 2-3 times a year and have an infra structure of other physicians to help evaluate proposed research projects.

RELATIONSHIP WITH APLA AND OTHER AIDS SUPPORT GROUPS:

It was reported that at the Board of Directors Meeting of Aids Project Los Angeles ("APLA") on August 20 the formation of NARF was discussed. It was also noted that NARF was negotiating to hire William Misenhimer as its Executive Director. Peter Scott, William Misenhimer, and Joel Weissman reported that there was obviously some concern about a new organization and their plans. They expressed a hope that the organizations would be complimentary. The APLA Board resolved to attempt to establish a joint committee to liaison together with NARF.

The mechanics of fund raising in various cities was discussed. Many cities have their own grass roots organizations for support of AIDS patients and education of the public. The delicate nature of obtaining support from those local organizations would be paramount to the success of any fund raising venture in those areas. William Misenhimer suggested ways in which this could be accomplished, such as co-sponsoring events, or giving a

percentage of the funds raised back to the local service organizations. It was the expressed desire of all present that we wanted to send a clear message to APLA that we wanted to work with them to have a mutually beneficial relationship. Upon motion duly made, seconded and unanimously carried, the following resolution was adopted:

RESOLVED, that our organization, through the Executive Committee work with various community based organizations to elicit support, cooperation and coordination.

REPORT OF THE EXECUTIVE DIRECTOR AND MISCELLANEOUS:

William Misenhimer reported that he had announced to the Board of Directors of APLA that he would be resigning as of October 1, 1985. This would allow for an orderly transition. He felt that up until that time he could devote a portion of his free time to NARF.

He asked that he be contacted if anyone knew of space (approximately 2,000 square feet) that might be donated for the first year.

Much work has yet to be done to select a CPA firm, public relations firm and a legal firm (Charles Larson announced that his legal services during the start up organizational phase of the foundation were donated "pro bono" and offered to continue as legal counsel at one-half the usual rate charged for similar services, once the organizational phase is completed).

Elizabeth Taylor wants to be involved in the National Organization as a working member of the board rather than just lending her name in an honorary status.

Burt Bacharach and Carol Bayer Sayer have written a song which they have indicated a willingness to donate to the Foundation. The Foundation would have the right to use the song in its campaign and the right to any proceeds that might derive from it.

Arnold Klein announced that other individuals, well known to all, have also expressed an interest in participating in fund raising.

William Misenhimer agreed to look into at least two public relations firms that have the ability to represent the Foundation nationally.

EXECUTIVE COMMITTEE MEETING:

Michael Gottlieb discussed the results of a meeting of the Executive Committee held August 17, 1985. There was a desire to have a board that is more heterogeneous, and more representative of different interests and groups. It was felt that a broad based

board of directors would have more impact and potential for fund raising than the presently constituted groups. Also there was a desire to decrease the number of directors to facilitate a combination with AIDS Medical Foundation, if that appears desirable. Dr. Gottlieb accepted the resignations of Christopher Hersey and David Sanders (as members and directors) to accomplish this. They were thanked for their participation in the organizational stages of the Foundation. The resignation of William Misenhimer was accepted so that he could assume his responsibilities as Executive Director of NARF.

To further develop the broad base needed in the Board of Directors, the name of Julius Krevans was discussed. Dr. Gottlieb volunteered to contact him and determine his interest.

The board voted favorably on asking Charles Kivovitz, M.D. and Bruce Decker, Co-Chair of the State AIDS Advisory Committee to become board members.

There being no further business to come before the meeting the President called a meeting for the following Wednesday at 7:30, and upon motion duly made, seconded and unanimously carried, the meeting was adjourned at 9:40 p.m.

Robert Winters, Secretary

MINUTES OF SPECIAL MEETING
OF BOARD OF DIRECTORS OF
NATIONAL AIDS RESEARCH FOUNDATION

AUGUST 28, 1985

A meeting of the Board of Directors of the National AIDS Research Foundation was called by the President and was held at the Bank of Los Angeles on August 28, 1985 pursuant to notice duly given. It was called to order at 7:55 p.m. by the President, Michael Gottlieb.

DIRECTORS PRESENT:

The following directors were present:

Sheldon Andelson
Bruce Decker
Michael Gottlieb
Arnold Klein
Charles Larson
Michael Roth
Rand Schrader
Peter Scott
Joel Weisman
Robert Winters

No directors were absent. (Charles Kirovitz, M.D. had not yet formally accepted a position as director.) Also in attendance was the Executive Director, William Misenhimer, former board member David Sanders, and three guests from the AIDS Medical Foundation:

Mathilde Krim, M.D.
Mr. Terry Biern
Mr. B. J. Styles

MINUTES OF MEETING OF AUGUST 21, 1985:

The minutes of the August 21, 1985 meeting were not available. Therefore, discussion of them was put off until the next meeting.

PROPOSAL FOR MERGER OF AMF AND NARF:

Michael Gottlieb thanked Mathilde Krim, Terry Biern, and B. J. Styles for coming from New York to further investigate a proposed merger of the two foundations. He paid respect to Dr. Krim and her group, AIDS Medical Foundation, for their pioneering efforts in beginning an organization to conduct much

needed research. He emphasized the friendly spirit of cooperation that existed in the meetings conducted over the preceding three days. The need for an organization on a truly national level was discussed.

Mathilde Krim thanked the board for their warm reception, and addressed the issue of the opportunity that was presenting itself to form a united organization, one that could aggressively go after funding on many levels. She cautioned that some individuals would have to step back and others might have to step aside to achieve a greater goal.

Sheldon Andelson indicated that he was frightened by the challenge, then encouraged us to overcome our fright and structure an organization that would capture the national imagination.

After comments by many of those assembled Michael Gottlieb began the reading of the proposal to merge AIDS Medical Foundation and the National AIDS Research Foundation:

Purpose

To create a truly national foundation to support research and develop public understanding to overcome the Acquired Immune Deficiency Syndrome (AIDS).

Chairmanship

Mathilde Krim and Michael Gottlieb would serve as Co-Chairmen of the Board of Directors.

Board of Directors

The board would be a new board comprised of 15-20 members approximately 1/3 selected by AMF, approximately 1/3 selected by NARF, approximately 1/3 selected for their ability to bring national recognition and major support to the Foundation. The new board would have diversity and heterogeneity to enhance the organization's appeal. Various names were suggested as individuals who would actively work on the board, as opposed to an Honorary Board.

The full board would probably only meet about twice a year, with an Executive Board that would meet about once a month and telecommunicate once a week.

A national Executive Director would be selected who would oversee regional fund raising. It was suggested that terms of the board members be stepped and that individual terms of office be established.

Name

The name of the combined organization would be "The National AIDS Research Foundation."

Scientific Advisory Committee

The foundation would have a Scientific Advisory Committee comprised of a select panel of the most distinguished researchers and clinicians which would set scientific policy, bring awareness of existing scientific developments, and be responsible for recommending to the full Board research proposals that would be funded (12-15 members, meeting twice yearly).

Scientific Council

The Foundation could also have a Scientific Council of distinguished scientists, drawn principally from outside the field of AIDS research, to provide an annual, outside review of the Foundation's overall scientific program (4-6 members).

Coordinator of Scientific Advisory Committee

The Scientific Advisory Committee would be organized by a "Coordinator" who shall serve a term of two years. Dr. Michael Gottlieb will serve as Coordinator for the initial term. After a term of two years, a new Coordinator would be elected by the Scientific Advisory Committee.

The Coordinator's responsibility would be to schedule and moderate meetings of the committee, oversee staff of the Committees in grant RFP and awards process, establish a system for progress report evaluations and publications funded by the Foundation, edit the newsletter published by the Foundation for the lay audience.

Both Drs. Krim and Gottlieb would be members of the Scientific Advisory Committee. They would select appropriate expert reviewers to evaluate Grant Proposals.

Foundation Policy

The Foundation would support research, however it would not conduct its own internal research projects.

Political Education

Political education, to the extent permitted by law for a not-for-profit Corporation would be conducted but not lobbying which is expressly prohibited in the Articles of Incorporation.

Previous Obligations

The AIDS Medical Foundation has an obligation to establish a Retrovirus Laboratory at St. Luke's/Roosevelt Hospital in New York.

The cost of this is \$500,000. Approximately \$200,000 has already been raised for this and two events are planned which should cover the additional approximate \$300,000.

A "sunset" date would be set for the termination of all fund raising for this project. In a meeting with David Geffen that afternoon to facilitate the merger, he promised to cover any shortfall that may occur.

Legal Procedure

A discussion ensued as to the best legal and technically correct way of effecting a merger. It was thought best to have this worked out by legal counsel of both organizations, or if not, worked out by one counsel and agreed upon by the other.

Other Discussions

- 1) J. Styles commented upon looking into States of Incorporation to see if there would be benefits accrued by incorporating in other states.
- 2) The Foundation would be filing a DBA (Doing Business As) The Rock Hudson AIDS Research Foundation, so that proceeds contributed in his name would go directly into our Treasury.
- 3) The suggestion was made to have "chapters" in different cities.
- 4) These chapters would work with local support groups already in existence and with gay organizations.

Michael Gottlieb thanked the members of the ARF not only for coming to Los Angeles, but also for their cooperation and far sightedness in working toward a merger. The guests then excused themselves during a short intermission.

Upon reconvening many issues were discussed, the most important being the vision of a truly national organization that could attract significant funds and augment the research against this devastating disease. Other discussions revolved around other potential candidates for the board of directors, the issue of accepting liabilities of AMF.

Open discussion ensued and was agreed upon by all present that if merger was recommended then all present members of the board should tender their resignation, allowing the Chairman to select individuals, whether or not they sit on the present board, to achieve our national goals.

Upon motion duly made, seconded and unanimously carried, the following resolution was adopted:

RESOLVED, that the Board of Directors of the National AIDS Research Foundation as presently constituted agree in concept to merge with AIDS Medical Foundation; under the broad guidelines established above.

There being no further business to come before the meeting, upon motion duly made, seconded and unanimously carried, the meeting was adjourned.

Robert Winters, Secretary

AIDS Advisory Committee
Meeting Minutes

August 16, 1985

San Diego AIDS Project
4304 3rd Avenue
San Diego, CA

COMMITTEE MEMBERS PRESENT

Bruce Decker, Chairman
Michael Roth, M.D., Vice Chairman
James Chin, M.D.
Stan Hadden
Michael Gottlieb, M.D.
Dick Pabich
Richard Hamilton, M.D.

COMMITTEE MEMBERS ABSENT

William Filante, M.D.
Sal Roselli

STAFF MEMBERS PRESENT

D.L. Gunter
Ed Mendoza

Mr. Decker called the meeting to order and reviewed the agenda items to be discussed. These included but not limited to:

1. ACR 118
2. School Policy on AIDS or ARC in Children
3. Statewide AIDS Plan
4. Contractors' Meeting
5. Alternate Screening Sites

Stan Hadden agreed to the follow up on AB 488 legislation as it relates to county test sites being exempt from liability. It was requested from staff that the past 12 months AIDS Committee meeting minutes be made available to members as the basis for the preparation of Committee required report (ARC-118) to the Director. Dr. Chin reviewed the current reorganization within the Department through all administrative levels up to the Governor's Office.

He also gave an outline of the process currently taking place within the Department in preparing the comprehensive AIDS statewide plan required by this administration.

Robert Anderson, M.D. was introduced by Dr. James Chin as the new Chief of the AIDS Section. Dr. Anderson is expected to be on board by mid-September. There was considerable discussion about staffing levels in the AIDS Section and the Chair requested staff to prepare a detailed report by the September meeting, to include an organizational chart, position classification, duty description and names of staff.

Mr. Decker requested that the Director of Health Services furnish a draft of the Statewide Comprehensive AIDS plans prior to the State AIDS Contractors meeting in early October so the Committee can have input and advice in the final preparation. Dr. Chin reported on the status of a National School Policy as it relates to AIDS in the school population. These guidelines are being formulated by a national committee of experts and Dr. Chin expects to receive a copy of these guidelines within the next couple of weeks.

Much discussion ensued around who needs to be informed if a school child has AIDS, rights of other parents to be informed, special educational facilities, and school insurance.

Dr. Richard Hamilton gave a report on the HTLV-III Antigen Assay and related issues. This report was read to the Committee and a copy is attached. Discussion of research and how expensive the development of an antigen test followed Dr. Hamilton's presentation.

Drs. Chin and Hamilton led in a discussion of the MMWR update on the Antibody Test for AIDS virus (copy attached). Mr. Decker commended Dr. Hamilton and his subcommittee on the work done and commented that this was an example of the Committee anticipating an issue instead of just responding to an AIDS issue.

Lillis Stephens discussed the problem of converting from group to individual insurance coverages and at-risk groups possible finding that rates have been increased 50 to 100%. There is no ceiling on increase cost. Stan Hadden was asked to check out, legislatively, how insurance ceiling can be capped.

The Committee will be inviting representative from both the Department of Insurance and the Department of Corporations to make presentations at the AIDS Contractors' meeting with the central theme, "take another look at your policy and make sure you are insured."

Dr. Chin reported on the State and Territorial Health Officers' meeting he recently attended in Madison, Wisconsin. He read an issue statement position that "isolation of AIDS patients at this time is not feasible control method and is not recommended by the disease control committee." This recommendation will be sent to STHO and Dr. Chin expects it to be adopted.

Dr. Filante is to make a report on the issue of AIDS home health care and medical at the next advisory meeting.

Dr. Chin also reported on the difference in counting AIDS reported morbidity: 1) by area of diagnosis and 2) by residence of patients.

Dr. Chin stated two set of "books" are maintained so most counties can be credited with legitimate AIDS count. The afternoon session began with an update of current legislations. Stan Hadden will give a report at the next meeting on status of AB 600 and SB 1251. There needs to be a review of SB 1327 reference Medi-Cal paying conversion cost when the medical condition is catastrophic. Stan Hadden will also follow up on legislation needs as it relates to conversion cost increases from group to individual and the need to have a "cap" on cost increase.

Dr. Gottlieb again stressed that the public should check their insurance policies to see if there are exclusions to any illness, including AIDS.

By the September meeting a rough draft of an insurance coverage pamphlet should be ready for review by the Committee. The theme of the pamphlet will be "check your policy" for possible exclusions to certain illness, including AIDS.

J. Allen McCutchan, M.D., Research Director, San Diego Medical Center, gave a comprehensive report on the need for Home Care for AIDS patients and the tremendous burden this need places on the hospital, staff and resources. He stressed the need to remodel AIDS wards for hospital care, support from the state to counties in sharing the financial burden and the need for health provider training/support for "stressed-out" condition of AIDS staff.

Bruce Decker stated this need should be addressed in the Comprehensive Statewide AIDS Plan that the Committee will have input. Mr. Hadden added that SB 1251 will include a pilot program to fund home care hospice care for AIDS patients as a more humane as well as cost-effective alternative.

A report was given on the status of the HTLV-III Antibody Alternative test sites. Twenty-five (25) of the thirty-one (31) designated counties are operational. Concern was expressed by the Committee that there may be the need to redirect any excess monies toward those whose test are positive. Discussions concluded that all patients, regardless of tests results, were a prime at-risk group and additional prevention and education messages could be directed to this captive population if resources were available.

A motion was made to request the Director of Health Services to evaluate the cost of alternate testing sites and if unexpended resources are anticipated that additional educational efforts be directed to those citizens concerned enough to take the antibody test. The vote of the Committee was five (5) "yes," Dr. Hamilton, "no," and Dr. Chin, abstain.

Mr. Russ Toth reported on the Contractor AIDS Conference in Los Angeles on October 3 and 4, 1985, with a good mixture of general sessions, poster sessions and AIDS workshops. Sharing of places, ideas and activities between our 28 contractor groups will make for stronger AIDS programs statewide.

Staff was requested to prepare reports on FY 1984-85 budget expenditures and a progress report on FY 1985-86 contracts.

The next meeting is scheduled for September 20, 1985 in Los Angeles, California.

Meeting ajourned

CALIFORNIA AIDS PROJECT

AIDS ADVISORY COMMITTEE MEETING REPORT

The AIDS Advisory Committee met on September 7, 1984, at the San Francisco Department of Health. Self-introductions of committee members, Department of Health Services (DHS) AIDS staff, and observers were made. The Governor's final appointee, Michael Gottlieb, M.D., was welcomed.

I. OLD BUSINESS

- A. The minutes of the previous AIDS Advisory Committee meeting were approved.
- B. The Committee discussed the dilemma regarding state funding for counties where local resources are or are not available. Should the State penalize counties that have made AIDS a priority for local funds or should state monies be concentrated in currently unserved areas? It was suggested that this topic be addressed later and that funding guidelines be developed to 1) insure that all appropriate California groups are adequately served, and 2) stimulate local participation in AIDS services.
- C. Bill Krause suggested that there is too little money generally to address the growing AIDS crisis. Dr. Filante asked that the committee establish AIDS-related priorities and present them to the Director.
- D. Bruce Decker and Michael Roth, M.D., were nominated to Chair and Vice-Chair of the committee respectively. The vote for Decker as Chair and Roth as Vice-Chair was unanimous.

II. AIDS STAFF REPORT AND COMMENTS

- A. Health services staff reported on current field activities including 1) the Los Angeles AIDS Community meeting requested by Martin Finn, M.D., and 2) the status of the RFP/proposal process for new AIDS contracts.
- B. The Advisory Committee requested that staff submit: 1) a two-page summary of each proposal as required in the RFP; 2) a proposed budget; and 3) a short staff evaluation with possible budget changes. After the deadline, staff should provide a total listing of all proposals with the first 20 or 30 in priority sequence according to staff evaluation.
- C. Senator Milton Marks addressed the Committee, emphasizing 1) the need to clarify San Francisco's inclusion in the AIDS RFP and the special efforts of staff in revising to meet this need; 2) the

need to devise a more equitable way to distribute AIDS education monies statewide such as using a "matching formula", so that, for example, for every \$5.00 raised locally for AIDS Education, the State would contribute \$1.00. By using such a formula, communities who have responded to the crises, such as San Francisco, will not be penalized, while those who have not responded will be motivated to begin the fight against AIDS; and 3) that education monies should not be diverted to other AIDS activities such as disease surveillance and state laboratory functions until a 65% state education funding ratio has been achieved.

- D. Dr. Filante discussed researching how emergency medical crisis funds may be sought in the legislature. Senator Marks made a commitment to the Committee to help obtain additional funding for AIDS. Dr. Filante also asked for a list of DHS priorities on contemporary health issues. He questioned why, if AIDS is considered a priority, DHS resources could not be further redirected to deal with the crisis.
- E. Dr. Roth felt the committee has a responsibility to inform the Director that more money is immediately needed for AIDS activities. Doubt was expressed regarding the Department's ability to redirect budgeted funds.

III. NEW BUSINESS

A. Allocation of remaining AIDS funds.

James Chin, M.D., advised Richard Emmons, M.D., Chief of the State's Virology Laboratory, that he should be "tooling up" for the AIDS testing activities. Dr. Emmons agreed that he needs to begin working with the AIDS retrovirus, to develop protocols for the tests and to establish training and assistance capabilities for local laboratories which will be testing for AIDS. Present workloads, including testing for rabies and plague, prevent him from diverting resources from other lab responsibilities.

Stan Halden asked whether these activities will be a duplication of work done at the federal level. Dr. Chin explained that federal guidelines are not always applicable to local labs and that the State Laboratory will be looked to for advice and interpretation of lab protocol and procedures.

- B. Gary Crawford gave an overview of surveillance and field services stressing the importance of both in implementing information/education activities.

AIDS surveillance should therefore progress into a more active role. Key personnel in hospitals throughout the State of California should be contacted regularly, depending on local need. These personnel would include infection control doctors and nurses,

pathologists, and dermatologists. A regular program of visits would lead to more efficient reporting and a stronger surveillance base.

Active AIDS surveillance in served geographical areas, as well as underserved areas of California, will also show how effective community-based organizations, as well as city and county governments, have been in disseminating information and education to high-risk groups, health providers, and the general public. This will enable the state to assist certain programs dealing with information and education activities to become more efficient, and to direct needed information or education into areas where no organizations exist.

- C. The next AIDS Advisory Committee meeting was scheduled for Friday, October 12, 1984, in San Francisco from 10:00 A.M. to 2:00 P.M. and will be convened for the review and recommendation of new AIDS contracts.
- D. The AIDS Advisory Committee then went into an Executive Session to formulate its final recommendations.

IV. AIDS ADVISORY COMMITTEE MEMBERS PRESENT

CHIN, James, M.D. - Director of Health Services Designee, California Department of Health Services, Infectious Disease Section

DECKER, Bruce - Governor's Appointee, San Francisco, California

FILANTE, William J., M.D. - Governor's Appointee, Sacramento, California

GOTTLIEB, Michael, M.D. - Governor's Appointee, Los Angeles, California

HADDEN, Stan - Senate Appointee, Sacramento, California

HAMILTON, Richard R., M.D. - Governor's Appointee, San Francisco, California

KRAUSE, Bill - Assembly Appointee, San Francisco, California

ROSSELLI, Sal - Senate Appointee, San Francisco, California

ROTH, Michael, M.D. - Assembly Appointee, Santa Monica, California

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Director of Health Services
Designee

PMSB

file Bruce
Decker

Health Policy & Research Foundation of California

Bruce B. Decker
President

MEMORANDUM

To: Board of Trustees
Co-Chairs, Executive Evaluation Committee
Members, Executive Evaluation Committee

From: Bruce B. Decker *Bruce Decker*
President and Acting Executive Director

Date: February 5, 1987

Re: Presentation Documents for Review

Enclosed you will find the presentation of the priorities developed upon which we propose to base the Master Plans for treatment and prevention of AIDS in California.

Please review them. The deadline for getting written comments to us is Friday, February 20, 1987. We welcome and encourage your comments but in order to have them incorporated into the presentation documents, we must receive them at our office in Los Angeles no later than the close of business, Friday February, 20th.

Our meeting details:

Presentation of Revised Priorities
Thursday, February 26, 1987 1:00pm
350 McAllister Street, Room #1194
San Francisco

At the conclusion of the meeting, we will have an informal reception honoring Dr. James Chin in recognition of his long and fine service to the AIDS community.

We will send out the first draft of the Master Plans on about April 1st. asking for your comments by April 26th. in order to meet for our final presentation on May 1, 1987, 1:00pm in Los Angeles.

Enclosed you will also find an agenda and updated list of the Evaluation Committee. Please let us know if you would like to suggest additional individuals to be included.

Thank you for your interest and prompt reply.

CALIFORNIA'S WAR ON AIDS
EXECUTIVE EVALUATION COMMITTEE

Meeting Agenda

Thursday, February 26, 1987
1:00pm
350 McAllister Street, Room #1194
San Francisco

- I. Introduction of Co-Chairs and special guests (Roth/Decker)
- II. Presentation of revised priorities (Gorman/Ogle)
- III. Discussion/public testimony* (Co-Chairs)
- IV. Presentation of Plan preparation process (Gorman/Ogle)
- V. Discussion/public testimony* (Co-Chairs)
- VI. Adjournment

note: The meeting will be followed by an informal reception honoring Dr. James Chin, who will shortly be leaving the California Department of Health Services.

* Public testimony will be limited to 5 minutes per witness. We encourage written testimony.

CALIFORNIA'S WAR ON AIDS
EXECUTIVE EVALUATION COMMITTEE

CO-CHAIRS

PLEASE NOTE: Affiliations are listed for identification purposes only.

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Donald Francis, M.D., D.Sc.
CDC AIDS Advisor, California Department of Health Services

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Associate Professor of Medicine, University of California, Los Angeles

Alan McCutchan, M.D.
Associate Professor of Medicine, University of California, San Diego

Warren Winkelstein, M.D., M.P.H.
Professor of Epidemiology, University of California, Berkeley

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UCLA Public Health Department

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Senate Office of Research

Dean Echenberg, M.D.
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Assemblyman, San Rafael

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AIDS Interfaith Council

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Mr. Paul Harder
URSA Institute

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Inland Counties Health Services Agency

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Mr. Bill Haskell

Mr. John F. Horrell
American Red Cross

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Mr. Mark Madsen
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Mr. David Mallon
Los Angeles Shanti Foundation

Mr. Chris Marshall

Mr. Tony Marshall
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* Designates a Member of the Board of Trustees

Health Policy and Research Foundation
of California

CALIFORNIA'S WAR ON AIDS

Prevention/Treatment Policy Recommendations

First draft
(not for publication or distribution)

February 5, 1987

Authors

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Michael Gottlieb, M.D.

Donald Francis, M.D., D.Sc.

Alan McCutchan, M.D.

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Chairman

Michael Roth, M.D.

President and Acting Executive Director

Bruce B. Decker

TREATMENT

The purpose of this paper is to encourage discussion on the prioritizing of treatment services for the HIV infected community in California over the next 4 years. Through the Health Policy and Research Foundation's initiative and with your support and input, the Institute of Medicine's Confronting AIDS recommendations will be adapted and applied to California situation. The overall goal of this collaborative process is to establish a cost effective and efficient continuum of health care for people with HIV infection applicable to metropolitan and others area in California. This will be achieved over the next 4 months through meeting the following objectives.

- (1) Establishing models of community based care through gathering and analyzing community needs assessments data on existing services, projected target populations and demonstration projects.
- (2) Prioritizing unmet and anticipated gaps in the health care continuum.
- (3) Recommending which existing services need to be expanded or modified and which new services will need to be developed.
- (4) Establishing agreed goals and objectives for a feasible 4 year plan for the State of California and how it might be implemented and administered throughout the regions.
- (5) Highlighting policy issues which detract from the successful implementation of a cost efficient health care continuum for HIV infection and recommending policies and procedures which will support the overall goal of the project.

1. Establishing Models of Community-Based Care

Institute of Medicine report Confronting AIDS strongly supports the development of non-hospital centered systems of care for people with HIV infection:

"The real power of coordinated AIDS care plans is found in the integration of hospital and outpatient care with those facets of patient care based in the community"

Studies at the Institute for Health Policy and Research have illustrated the efficacy and cost effectiveness of a system of care which primarily relies on an integration of traditional hospital care with strong case management and discharge planning. The system is only effective if it is underpinned by a variety of community based services ranging from shelter programs and nursing homes to volunteer counseling/support services.

Existing home health and attendant care projects throughout the State are demonstrating the importance of nursing, hospice and home health care, both to patients and those chiefly responsible for health cost reimbursement - the insurer, employer or the government.

The results of these demonstration projects will not be fully available to us until January 1988, but we should have some initial useful data by the June 1987.

The Shanti project in San Francisco has an important residential component for those people with AIDS who would otherwise be homeless. Other shelter programs are currently being developed in Los Angeles with AIDS Project, the Archdiocese of Los Angeles, and Minority AIDS Project. The Coming Home Hospice Project in San Francisco, is another new model of AIDS treatment with an interesting history, relevant to policy regulation and licensing issues. In developing appropriate models of care for people with HIV infection it will be important to identify and highlight bottlenecks in the existing licensing and health care system which will need to be reformed if an appropriate continuum of health care is to exist. Without these important alternative residential facilities, many people with HIV infection will be forced to remain in costly, increasingly crowded and inappropriate hospital facilities. At University of Southern California/Los Angeles County Medical Center, it is estimated 15%-20% of AIDS patients at an approximate cost of \$1,000 per day are unable to be discharged because an appropriate facility does not yet exist.

In Los Angeles 148 skilled nursing facilities were surveyed in May 1986. Although interested in developing AIDS education for staff, only 2 of them were currently accepting people with AIDS. Demonstration projects for skilled nursing facilities, (particularly interested in cost containment) are operating in Northern California and discussions are in progress for a Southern California based project. These projects will be particularly important to statewide communities who are currently forced to keep AIDS patients in acute and subacute facilities, making the cost of care unnecessarily expensive, and the type of care inappropriate to patients wishes or needs.

In developing data, and demonstration projects, there is also a need to facilitate comparison of patients, their health outcomes, quality and effectiveness of care and the cost associated with its provision. Guidelines for data collection in all demonstration projects should at minimum address:

- (1) patient demographic data
- (2) medical status at entry
- (3) outcome measures (including longevity or the number of days spent out of the hospital as a surrogate for the quality of life)

It is desirable to rapidly establish optimal modalities for cost effective care before the anticipated large increases in the number of patients take place. Standardization of data collection would be helped if perhaps all public and private grants awarded to AIDS service providers would require them to collect and monitor certain information relating to cost, type and quality of care while ensuring client confidentiality.

2. Prioritizing Unmet and Anticipated Gaps in the Health Care Continuum

We will utilize those community needs assessments and collaborative regional planning reports resulting from the Robert

Wood Johnson Foundation's 1986 AIDS Program. Four metropolitan area, San Francisco, Orange County, San Diego, and Los Angeles developed proposals which will be useful to us as we prioritize the unmet needs of these regions. Other areas have sent us planning information which will also help us develop a statewide needs assessment. The URSA Institute's Statewide needs assessment will also be available. A recent planning document from San Francisco (Plan for 1987/88) further demonstrates the needs and priorities in that region.

Overall treatment priorities for California still needing to be addressed appear to fall into the following categories.

- (a) Comprehensive case management systems for people with HIV infection including hemophiliacs and children.
- (b) Non-hospital based community care facilities, including skilled nursing facilities, residential care facilities, and programs utilizing home health/hospice principles.
- (c) Treatment programs sensitive to the black and Hispanic communities.
- (d) Programs and treatment facilities to treat alcohol and drug abusers with HIV infection and those with dementia.
- (e) HIV Treatment Centers where information and access to clinical drug trials will be available to an increasing population of HIV infected individuals seeking information and treatment. These may develop from existing outpatient clinics already established in key target areas, working in close cooperation with hospitals dealing with appreciable numbers of patients with HIV-related diseases.
- (f) Programs to develop volunteer recruitment, training and support systems integral to the health care continuum.

Studies have shown the importance of existing community based agencies and volunteers in the provision of care and the minimizing costs. Incentives could be given to existing volunteer/community based agencies to develop a Statewide recruitment, training and support systems for volunteers which could be utilized in all regions by various ethnic, religious and socioeconomic communities.

3. Recommending Which Existing Services Need to be Expanded or Modified and Which New Services will Need to be Developed

Once agreed, the overall treatment priorities for the State could be applied to local regional situations as a mandate for elected representative forums which we may call Regional AIDS Councils. Different regions may have different priorities. San Francisco, for example may have a strong case management system already in place but needs more nursing homes.

The California Department of Health Services Office of AIDS is developing a regional network of providers and patients throughout the State. These 8 regions will have designated staff, funding, special needs and specific goals and objectives. The Robert Wood Johnson Foundation encouraged service providers in metropolitan areas to collaborate together and submit one proposal outlining their agreed needs and prioritizing new programs. Through suggested Regional AIDS Councils, the ongoing planning, monitoring and evaluation of these programs would be principally local and representative of public and private interests and skills. This process, particularly in Los Angeles was the conduit for 75 AIDS related organizations to work together. Funding sources

should be encouraged to further develop this collaborative process when requesting regional proposals. This system would improve the existing competitive RFP process through encouraging service providers to share information and maximize limited resources. This system would also facilitate the development of agreed data collection, case management systems, volunteer and caregiver support systems needed on the scale required to meet the AIDS epidemic. These Regional AIDS Councils could be elected by existing care providers, representatives of health, mental health, academic, religious, political, and business communities.

The Council could also reflect the various components of the necessary health care continuum such as hospitals, outpatient clinics, skilled nursing facilities, community based agencies, etc. The Councils could be provided with technical expertise in management, communication systems, team building and long term health planning.

Representatives of the 8 Regional AIDS Councils could form the nucleus of the State's AIDS Council where overall management, resource allocation, and health planning could be determined.

4. Establishing Agreed Goals and Objectives for a Feasible Long Range Plan for the State of California and How it Might be Implemented and Administered Throughout the Regions

Through gathering and analyzing information, reaching agreement on prioritizing needs and resources, expansion of programs and election of local Regional AIDS Councils, and a State AIDS Council, A statewide strategic plan could be in operation within 6 months, coordinated through the California Department of Health Services/Office of AIDS. In establishing goals and objectives, The State AIDS Council could focus on the following areas:

(a) Ongoing program monitoring and evaluation.

It is important for us to immediately evaluate the existing health care system from the client/patient perception. This will not only ensure quality control, but would help to develop a comprehensive case management system, showing weaknesses or duplication in the care continuum and provide optimal cost efficient care (This may be developed in conjunction with a local AIDS ombudsman program, similar to evaluation and patient grievance procedures operating in New York).

(b) Ensuring the provision of appropriate models of care and numbers of facilities which are efficient and cost effective in the treatment of HIV infection throughout the State.

Once we have established models of care which meet our goals and objectives, it is important that public and private funding be made available to expand these programs where they are needed.

(c) Financing of care issues.

The cost of care should be distributed equitably through public/private reimbursement following the Institute of Medicine's recommendations. Some financing of care issues outlined in the report relevant for California are:

- o Insurers may not cover individuals with HIV infection or discriminate against people whose behavior or suspected behavior may put them at risk for HIV infection.
- o Insurers would like to be able to assess the financial risk the contract entails them and be permitted to use reasonable 'tools' to ascertain this.
- o Gaps may exist in the coverage provided by insurance or public programs (i.e. experimental therapy or community based care such as home care).
- o Use of the CDC definition of AIDS as a criterion for eligibility for certain types of financing (Medi-cal) is limited because it excludes other severe HIV associated conditions that may be equally disabling.
- o The two year waiting period for Medicare qualification excludes most individuals with AIDS who do not survive that long.
- o There is little data on the cost of medical care for ARC and seropositive individuals and yet these are the majority of people who will be utilizing health care over the next 5 years.
- o Certain geographic areas may have a disproportionate burden of reimbursement costs of care for AIDS patients in some hospitals.
- o Pediatric AIDS patients are increasing and need a complete range of services depending on parental support, if the parents themselves are dead or unable to manage.
- o Many AIDS patients with resources and health care coverage are easily impoverished by the loss of employment, hospitalization and other health related costs. A proper analysis of insurance for people with AIDS/ARC also needs to consider disability, wage replacement and possibly death benefits as well as medical care coverage.
- o Many AIDS-affected individuals may have no health insurance.

(d) Monitoring and addressing relevant policy issues (which are outlined in detail in the last objective).

The State AIDS Council should be empowered to initiate policy reform.

5. Highlighting Policy Issues Which Detract From the Successful Implementation of a Cost Effective Health Care Continuum for HIV Infection and Recommending Policies and Procedures Which Will Support the Overall Goal of the Project

(a) A variety of eligibility questions would need to be answered in the process of developing a comprehensive system of care and reimbursement for HIV infected individuals. These include establishing criteria for allowing individuals to participate in a health care/reimbursement scheme, the HIV related conditions that would be covered and the grounds for revision of eligibility criteria.

(b) An issue in the design of health insurance schemes, both private and public, is the question of what methods of providing benefits impart the most appropriate incentives to both providers and patients. If treatment of AIDS in settings outside of acute care hospitals generally prove to be more cost effective than longer hospitalization, than covering treatment in these settings is

desirable and lack of coverage provides an inappropriate incentives to use hospitals.

(c) If reimbursement for care for AIDS and other HIV related conditions fall subsequently below the cost of actual care, then hospitals and other facilities may have incentives to turn away AIDS patients.

(d) Issues arise around incentives to seek care which provides treatment for HIV infection and prevention. It is critical to examine ways in which the current system or any new health care financing support system be modified to help persons at risk avoid infection.

(e) There is a need to balance public/private coverage in the financing of care for HIV infection. With 40% or more of AIDS patients covered under Medicaid, it appears likely that future financing of AIDS care will be necessarily involve substantial public programs and funds. The scheme could be designed to shift the current balance in either direction or to maintain the status quo.

(f) Financial equity is another policy consideration where region within the State are expected to bear the rising cost of treatment. (By 1991 we anticipate 30.8% of projected AIDS cases to be living outside Los Angeles and San Francisco who will each have 33% - 36% of remaining cases).

(g) Incentives are needed to encourage existing nursing homes and hospitals to be able to operate skilled nursing facilities for HIV infection or dedicated AIDS units. These incentives could include an increase in the Medi-cal reimbursement rate to reflect realistic cost of care for patients.

(h) It is preferable that solutions of the problems arising from the financing of care for HIV infection be achieved within a mechanism that ameliorates problems existing in general for the financing of care for other serious illnesses. Measures could include national health insurance for catastrophic illnesses or state-based pools for persons medically at high-risk.

(i) Licensing and regulation procedures for skilled nursing facilities, hospital swing beds, adult day care centers, home health/hospice care facilities and residential facilities for the homeless will need to be revised to simplify the process of establishing on a large scale, community based models of care to alleviate the present gaps in the health care continuum.

PREVENTION

I. Introduction

The California Department of Health Services using CDC estimates projects a cumulative total of nearly 50,000 cases of AIDS in the State by 1991 with 37,000 deaths. By the end of 1991 nearly one-third of these cases are expected to come from outside the San Francisco and Los Angeles metropolitan areas. Had an adequate and well orchestrated prevention program been in place, many of their cases would not occur. Certainly unless an adequate and effective program for prevention of HIV transmission is implemented with some immediacy, California can expect to see a continued dramatic rise in cases. At a cost of \$90,000 per case, by 1991, insurers and taxpayers will have borne a burden of more than \$4 billion in health care costs.

In "Prevention of AIDS in the United States" (in press in J.A.M.A.) Donald Francis, M.D., D.Sc. and James Chin, M.D., M.P.H. point out:

"with our current understanding of AIDS it is clear that virtually all future infections can, at least theoretically be prevented. Individuals given the opportunity (i.e. information, motivation and skills) should be able to modify their behaviors to protect themselves from infections. The major question is can our society unite to effectively impact the needed information, motivation, and skills to stop this epidemic? The answer to this question depends on first, having commitment to effectively intervene; second, developing a reasonable scientifically and socially sound intervention plan; and third, instituting that plan as rapidly as possible."

We believe that our State can unite effectively to develop the needed strategies required to halt the transmission of the virus and that a reasonable, scientifically and socially sound intervention plan can be developed. To this end, a unique effort has been undertaken involving assessment and planning among the California Department of Health Services, the Health Policy and Research Foundation of California and a large and representative group of scientists, health policy and community experts.

The plan will encompass three phases: the first is the development of a set of "model standards" or guidelines for primary prevention informed by such documents as the 1986 Institute of Medicine report, the Surgeon General's report, and relevant primary prevention literature as well as the expertise of the State's public health, scientific and community experts. There will be a close working relationship with the Department of Health Services. Previous to this effort no cohesive set of standards for AIDS prevention has existed. While the standards will not be "etched in stone" they will constitute general guidelines and criteria by which to give some measure of organization and prioritization to the State's prevention

efforts. The Committee's input is sought in this initial effort and any ideas would be most appreciated, preferably in writing, prior to February 20th.

Phase two will be the actual needs assessment. Donald Francis, M.D., D.Sc. and Michael Gorman, Ph.D., M.P.H. will undertake to establish the baseline of current State prevention activities and to ascertain gaps as measured against the "model standards". While information will be collected on Statewide efforts, time and financial constraints require that the effort be narrowly focused. In this regard, three basic categories will be looked at. Preventive epidemiology (including case reporting and surveillance activities), interventions (including educational, informational and skill building activities and evaluations of those programs), and thirdly, the size, socioeconomic composition and accessibility for primary prevention of populations at risk will also be determined in the various settings. Phase III will be the writing of the final report to be finalized by May 1, 1987.

A. Preventive Epidemiology

The State's needs for preventive epidemiology will be assessed through the auspices of the State Department of Health Services and the various county health departments.

Primary activities about which data to be obtained will include:

- (1) Surveillance activities for AIDS and ARC by county and State health departments.
- (2) Seropositivity data from ATS centers, family planning clinics, (if available) as well as blood banks, hospitals, jails, methadone treatment centers and surveys of high risk populations; gay/bisexual males and IV drug users, hemophiliacs, prostitutes, sexually active heterosexuals, etc. and other relevant populations. Also any general population surveys that are available.
- (3) Epidemiologic research in the areas of the natural history, biology and behavioral epidemiology of HIV infection.
- (4) Relevant STD data (e.g. surveillance of rectal gonorrhea, syphilis, Hepatitis B)
- (5) Contact tracing data (under what circumstances implemented, personnel needed, cost effectiveness, etc.)
- (6) Estimates of personnel positions currently involved in prevention epidemiology efforts and future estimates of personnel needed to undertake these various activities.

In terms of preventive epidemiology, the Institute of Medicine's report Confronting AIDS, makes the following recommendations:

o The decision of whether to be tested for antibody to HIV should remain a matter of individual direction, given the array of potential risk and benefits that the test poses for those tested. Testing should be encouraged in light of its potential public health benefits. Mandatory screening of at-risk individuals is not an ethically acceptable means in attempting to reduce the transmission

of infection. In addition, such mandatory program would not be feasible in an open society.*

- o Testing programs should be coupled with strong guarantees of confidentiality. Such assurances should perhaps be backed by punitive sanctions for unauthorized disclosure of antibody test results. The committee does not recommend compulsory reporting of seropositive test results.*

- o The committee does not favor the establishment or the use of compulsory measures for isolation or quarantine of AIDS patients or seropositive persons the general population. There may be need, however, to use compulsory measures, with full due process protection, in the occasional case of a recalcitrant individual who refuses repeatedly to desist from dangerous conduct in the spread of the infection.

- o Special precautions against the spread of AIDS and the AIDS virus may be necessary in closed populations, such as prisons, jails, mental institutions, and residences for the retarded. Such measures should be applied with caution and only as clearly necessary and should not be used or cited as models for compulsory programs among the general population.

- o As a general policy, children with AIDS should be admitted to regular primary and secondary classes. The CDC guidelines are recommended for further reference in this area.

- o The committee supports a vigorous program of early reporting of both AIDS and ARC cases (as soon as acceptable definitions for reporting ARC can be formulated) to local and State public health agencies under strict policies of identifiability.*

- o The committee urges that blood and plasma collection centers also establish administrative systems to further encourage self-deferral of donations and diversion of suspect blood to research while maintaining donor privacy.

B. Interventions

The second major area of assessment is concerned with information campaigns, counseling/skill building activities and the evaluation of the efficacy of these programs.

Basic target populations for informational/Educational campaigns include:

- > health care professionals
- > public officials
- > the general public
- > high-risk populations:
 - > gay/bisexual males
 - > IV drug users
 - > hemophiliacs
 - > prostitutes
 - > sexually active heterosexuals
 - > minority populations
 - > teenagers

In addition to education and information campaigns a number of programs have addressed counseling and skill building activities, either under the auspices of ATS centers, health departments or community based organizations. Relevant data on their programs needs to be ascertained.

Finally, analysis needs to be undertaken of those evaluations that are underway. The assistance of The URSA Institute and the State Department of Health Services will be utilized in this regard.

While baseline data will be assembled for as many counties as information is available, 5 counties will be selected for more in-depth site visits: San Francisco, Los Angeles, and three other counties, chosen to be representative of the range of State's diversity in geography and population will also be site visited. A survey instrument is being developed by the project leaders and will be utilized in the field settings.

To refer once more to the Institute of Medicine's Report:

Recommendations

o The major aim of AIDS education is modification of certain behavior with respect to sexual and drug use practices, such as unprotected anal and vaginal intercourse with those who are infected or at risk of being infected and sharing of injection equipment. In order to achieve this aim, educators and educational materials must be free to use clear and direct possibly colloquial, language that will be understood by those being addressed. The committee recognizes that the reluctance of governmental authorities to address issues of sexual behavior reflects a societal reticence regarding open discussion of these matters. However, it believes that governmental officials charged with protection of the public health have a clear responsibility to provide leadership and guidance when the consequences of certain types of behavior have serious health consequences.*

o Discussion of alternative sexual behavior that provides at least a large measure of protection against transmission of the virus must be conveyed to those targeted for AIDS education. The proper use of condoms, in particular, should be stressed, and condoms must be widely and readily available to the public. It can be no longer be assumed that unprotected heterosexual intercourse is safe. It probably is safe only in such situations as a long-term exclusive relationships in which both partners have not engaged in risk taking behavior or where both partners test negative for HIV infection after refraining from risk taking behavior.*

o Special efforts must be made to educate the population of intravenous drug users and their sexual partners about HIV transmission both by sharing of injection equipment and by sexual intercourse. This population is one of the least cohesive subgroups in the nation, and innovative methods for reaching it must be developed.*

o The total educational effort is the combined responsibility of all levels of government, and the private and philanthropic sectors must also participate significantly in this activity. Government agencies that are reluctant to use direct and colloquial language in the detailed contents of education programs must be able to accomplish their education goals by contractual arrangements with private organizations not subject to the same inhibitions.

o Special attention must be paid to AIDS education for young people in schools and colleges, many of whom are entering periods of

experimentation with sex and drugs. Frank discussion of behaviors that do and do not transmit HIV has become an urgent necessity for this target population.*

- o One of the most difficult high-risk groups to deal with in the current AIDS epidemic is IV drug users. More research, methadone and other treatment programs, detoxification programs, and testing and counseling services related to drug treatment programs are needed. If there are legal barriers to the implementation of such programs, these barriers should be dismantled.

- o AIDS education should be pursued with a sense of urgency and a level of funding that is appropriate for a life-or-death situation. Greatly expanded educational programs to effect behavioral change are necessary for high-risk groups and the public at large. These efforts should be supported not only by the government, but also by experts in advertising and the media.*

- o The committee believes that a total national expenditure based on a per capita prevention expenditure roughly similar to that made in San Francisco is a necessary goal.

- o The process of designing and implementing educational interventions to reduce the risk of HIV transmission, followed by evaluations of their effectiveness, will enable policymakers to evaluate over the next year or two the magnitude of effort needed to bring about a drastic reduction in the spread of HIV infection. It is possible that the amounts envisaged by the committee will not be sufficient to stem increases in the prevalence of infections, especially since some of the groups at risk are difficult to reach with conventional approaches, and since, despite the expenditures noted above the virus continues to spread in areas such as San Francisco, though at a reduced rate. More funding for prevention measures will be necessary if those envisaged here for 1990 do not prove sufficiently great to slow the epidemic.*

- o Any form, either direct or indirect, of discrimination against vulnerable high-risk groups for AIDS should be discouraged and prohibited by state legislation and, where appropriate, by federal regulation and statute. In a positive manner, participation by representatives of high-risk groups in policymaking bodies should be encouraged where appropriate and practicable, and the help of organizations representing high-risk groups should be enlisted for public service programs such as health education, personal counseling, and hospital and home treatment services.

C. Populations at Risk

In addition to assessing interventions as such, we will also collect information on the various populations at risk in particular to gain some perspective on educational and behavioral interventions and to obtain their perspective on prevention.

Prevention of HIV infection cannot be accomplished without insight into, and, good working relationships with the various populations at risk.

To this end, we refer once again to the National Academy of Science report Confronting AIDS:

Because effective drugs or vaccines to counter HIV infection are not now available, effective educational interventions are essential to limit the spread of the virus. However, previous experience with educational programs to promote behavioral change for disease

prevention is rather discouraging. There is a great need to explore novel approaches in AIDS-related education and to vigorously examine the relative efficacy of various approaches.

Social science research should be directed toward the following goals:

- o Establishing the demography of heterosexual, homosexual, and IV drug use behaviors and the characteristics of the groups that practice different patterns of behavior.
- o Identifying credible information sources for various groups and opinion leaders.*
- o Conducting experiments and demonstration projects on approaches to behavior change to understand what does or does not work.*
- Tracking discriminatory practices and their dynamics (Why is discrimination a problem in some areas and situations and not in others?).
- o Evaluating treatment, social service programs, and hospital management practices to understand what works and is cost-effective.
- o Studying the special problems of caring for addicted individuals and preventing transmission among IV drug users.*
- o Linking experimental educational programs with epidemiologic evaluation of their effectiveness in reducing the rate of seroconversion across the spectrum of populations at risk.*
- o Making comparative studies of international responses to the epidemic.
- o Studying the public's understanding of and attitudes toward AIDS and related issues in order to better design interventions to promote accurate awareness.*
- o Studying and analyzing the ethical and legal aspects of the AIDS epidemic.

* indicates high priority

Health Policy & Research Foundation

Bruce B. Decker
President

STATEMENT OF PURPOSE

Recognizing the potential impact of AIDS on California's economy and the relatively recent funding interest by a broad base cross section of government agencies, foundations, corporations, and major donors, a three part planning program seems prudent: first, to identify all AIDS related projects funded here in California; second, a needs assessment in order to avoid duplication of effort or ignoring of needs; and third, the ongoing coordination of the various programs.

The Health Policy and Research Foundation was founded to do so in the Spring of 1986 at the suggestion of Kenneth Kizer, M.D., MPH, Director of the California Department of Health Services. Its Board and Advisors represent the most eminent and involved AIDS sensitive physicians, researchers, educators, public officials, service providers, civic leaders, and professionals ever assembled.

The No on 64/Stop LaRouche campaign, the Surgeon General's report and the National Academy of Sciences reaffirm that cohesive and strategic planning are critical.

Continuing California's tradition of leadership in meeting the challenges of AIDS, the Foundation is launching the much needed report preparation of all Federal, State, local and private sector AIDS programs and subsequently a report of anticipated needs resulting from the analysis. Subsequently, the Foundation will also be launching a corporate involvement campaign among California's major employers to assist them in dealing with AIDS issues.

Recognizing that funds available are limited and that needs will increase greatly, the Foundation is committed to maximizing the impact of programs through coordination, cooperation and the avoidance of unnecessary administrative and overhead expenses.

Working heavily with volunteers, the Foundation has a minimal staff and overhead expense. The small investment required for funding its activities will be worth it, and will pay off many times over during coming years, helping to maximize funds available and minimize the fiscal and emotional impact of AIDS on all Californians.

Health Policy & Research Foundation

Bruce B. Decker
President

BOARD OF TRUSTEES

Bruce B. Decker, President

Los Angeles

Founder and Finance Chairman, No on 64/Stop LaRouche Campaign
Chair, California AIDS Advisory Committee
Chair, California Strategic Planning Commission
Assisted in the founding, American Foundation for AIDS Research
President, Concerned Americans for Individual Rights

Stan Hadden, Secretary

Sacramento

Special Assistant to State Senate President David Roberti
Member, California AIDS Advisory Committee
Member, California Strategic Planning Commission
Member, California Department of Mental Health AIDS Task Force
Member, Sacramento Mayor's AIDS Task Force Board
President, Sacramento AIDS Foundation

Larry Bush

San Francisco

Special Assistant to Assemblyman Art Agnos Member, Elected Officials
Commission Member, California Strategic Planning Commission
Member, Executive Finance Committee No on 64/Stop LaRouche Campaign

Rob Eichberg, Ph.D.

Los Angeles

Clinical Psychologist, private practice
Founder, Municipal Elections Committee of Los Angeles (MECLA)
Advisory Board Member, Southern California CARES Program
Fundraiser for MECLA and AIDS Project Los Angeles
Member, AIDS Task Force, Gay and Lesbian Community Services Center
Member, California AIDS Strategic Planning Commission
Consultant, Stop AIDS, San Francisco
Co-Creator, The Advocate Experience

Donald Francis, M.D., D.Sc.

Berkeley

Centers for Disease Control Advisor to the California Department of
Health Services
Former Coordinator, AIDS Laboratory Activities, Centers for Disease
Control
Former Assistant Director, Hepatitis Division, Centers for Disease Control
Former World Health Organization Small Pox Advisor, to Sudan, India,
Bengaladesh

Georgia Garrett Norris, Esq.

Santa Ana

Attorney, private practice specializing in gay/lesbian issues
Member, Lawyers for Human Rights Member, American Civil Liberties Union
Founding Member, Elections Committee of the County of Orange (ECCO)
Board Member, AIDS Services Foundation

Health Policy and Research Foundation
Board of Trustees
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E. Michael Gorman, Ph.D, M.P.H.

Los Angeles

Research Coordinator, Robert Wood Johnson Health Services Project,
Los Angeles
Epidemiologist, Public Health Service Officer, Epidemiologist Intelligence
Service, Centers for Disease Control
Faculty Member and Facilitator, American Public Health Association Workshop
on Strategies for Collaboration on AIDS Issues
Project Coordinator, AIDS Prevention/Health Education Project, Division
of Health Education

Dennis McShane, M.D.

Redwood City

BAYMEC Liaison
Member, Executive Finance Committee, No on 64/Stop LaRouche Campaign
Member, California AIDS Strategic Planning Commission

Steve Morin, Ph.D.

San Francisco

Member, Northern California Executive Finance Committee, No on 64/
Stop LaRouche Campaign
Chair, California Council on Mental Health
Chair, State Psychological Association
Member, California AIDS Strategic Planning Commission
Member, Department of Mental Health AIDS Task Force

Dick Pabich

San Francisco

Northern California Coordinator, No on 64/Stop LaRouche Campaign
Member, Northern California Executive Finance Committee, No on 64/
Stop LaRouche Campaign
Member, California AIDS Advisory Committee
Administrative Analyst, University of California, San Francisco

Michael Roth, M.D.

Los Angeles

Vice Chair, California AIDS Advisory Committee
Member, California AIDS Strategic Planning Commission
Staff, AIDS Center, University of California, Los Angeles
UCLA Men's Study Advisory Board

Peter Scott, Esq.

Los Angeles

Founder, Municipal Elections Committee of Los Angeles (MECLA)
Media Director, No on 64/Stop LaRouche Campaign
Board Member, National Gay Task Force
Co-Manager, No on 6 Campaign
President, Mixner & Scott, Inc.
Co-Chair, California AIDS Strategic Planning Commission
Former Board Chairman, AIDS Project Los Angeles

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Lillis Stephens

San Diego

Chair, Hemophilia Council of California
Member, California AIDS Advisory Committee
Member, California AIDS Strategic Planning Commission
President, Hemophilia Association of San Diego
Member, San Diego County AIDS Task Force
Member, Committee on Juvenile Justice, San Diego

Tim Wolfred, Ph.D.

San Francisco

Executive Director, San Francisco AIDS Foundation
Member, California AIDS Strategic Planning Commission
Board of Governors, Community College District, San Francisco
Board Member, AIDS Action Council, Washington, D.C.
Board Member, National AIDS Network
Board Member, Hospice of San Francisco
Board Member, Economic Opportunities Council
Member, University of California, San Francisco, AIDS Health Project

Health Policy & Research Foundation

Bruce B. Decker
President

December 10, 1986

Michael S. Gottlieb, M.D.
American Foundation for
AIDS Research
2436 Washington Avenue
Santa Monica, California 90403

Dear Michael,

Your role in leading California's model AIDS response program is widely recognized. I, and many others, genuinely appreciate the commitment you have made to finding humane, logical and cost effective solutions to the complex problems AIDS presents.

The Surgeon General's report, combined with the National Academy of Science report and the Proposition 64 campaign, clearly illustrate the next great challenge we face: that is the need to, as the PHS/Coolfont report concludes,:

"develop a coordinated Federal, State and local response to manage the health service and health financing crisis posed by the escalating AIDS epidemic. This response must reflect the pluralistic character of the American health care system, and must involve the coordinated participation of public, private, and voluntary sectors as well as ambulatory, in-hospital and long term care providers."

We, working in collaboration with the U.S. Department of Health and Human Services, the California Department of Health Services, the Health Officers Association of California, the California Association of AIDS Agencies, and the University of California AIDS Research Task Force, among many others; are embarking on the development of a long term strategic plan in order to maximize the resources available in meeting current and future AIDS related needs here in California.

We are calling it "CALIFORNIA'S WAR ON AIDS". We will canvass resources available and anticipated needs making recommendations regarding how each sector of our society can help fill future financing and resource needs. We will look at the needs for training, continuing education and psychological support for institutional and community based research, mental health, prevention, and treatment providers. At the same time we will look to develop comprehensive delivery systems for those at risk and suffering from AIDS in each of these four major areas.

In addition to promoting extensive prevention education programs, our particular concern will be the development of organized consortia of service delivery systems responsive to the care of AIDS patients including all the necessary components of ambulatory, hospital,

Michael S. Gottlieb, M.D.
December 10, 1986
PAGE TWO

mental health, dental health, counselling, home health care and hospice care.

In a dramatic demonstration of the need for comprehensive strategic planning, the Public Health Service estimates that the direct health care costs of Californians with AIDS will be between \$2 to 4 billion in 1991. (We suspect it will be far greater in that the estimate is based on a \$46,000 per patient calculation. Not only do we experience a higher cost today, but the estimate is based on 1986 dollar values). With 25% of the estimated 145,000 national cases here in California (71,000 patients alive and 74,000 new 1991 diagnosed cases) plus an estimated 20% under-reporting of cases, AIDS will represent between 1.2% and 2.4% of the expected total of California's personal health care expenditures in 1991.

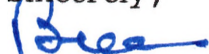
These estimates may have to be revised upward by 50% because of the increased need for care for the large population of patients with conditions associated with other infections and significant non-medical care costs necessary for the management of these illnesses.

Only by maximizing our resources will we be able to meet these incredible needs. Humane and cost effective care will require strategic planning and the development of community based health and social services support systems to reduce costs and enhance care.

We ask you to join our "WAR" by agreeing to CoChair our Executive Evaluation Committee. The Committee will meet twice in the first sixth months of 1987; once in February, where we will present our report of all AIDS programs funded in California, and in April, where we will present our report on anticipated needs for AIDS prevention, mental health, treatment and research programs for fiscal year 87/88. Our staff will gather the data and we will provide you with advanced copies so that nothing is released without your advanced approval.

I hope you will join us in our efforts and that if you have any questions you will not hesitate to call me at 2132789355.

Sincerely,



Bruce B. Decker
President and Acting Executive Director

BBD/dms

Enclosures: Board of Trustees
Statement of Purpose

BRUCE B. DECKER

January 30, 1986

MEMORANDUM:

TO: Michael S. Gottlieb, M.D.
FROM: Bruce B. Decker *BBD*
RE: San Francisco Fundraising Efforts

While it is unfortunate that sufficient entertainment was not secured to enable us to execute the proposed March 6th event, it is my firm belief that significant potential exists for a future event.

Sadly, due to professional responsibilities, I will be unable to devote full time to the organization and production of a postponed event.

However, I remain firmly committed to the Foundation's fundraising efforts in Northern California and will do everything I can to ensure the success of those efforts.

I believe we should take this opportunity to redouble our commitment to a successful Northern California event. I hope that the Special Events Committee will be able to meet with Charles Duggan, who has agreed, as a volunteer, to produce the event, and Steve Harris, who has agreed, as a volunteer, to co-ordinate the logistics involved. Both can be available, as can I, to be in Los Angeles on Friday, February 7 for an afternoon or evening meeting.

Clearly, I recognize my responsibility for the initiation of this event and my part in necessitating its postponement. I regret any error in judgement, and will translate my disappointment into redoubling my own commitment to serve in whatever capacity the Board may feel appropriate.

CC: Bill Misenhimer
Bill White

BBD/smp

February 6, 1986

TO: LER

FROM: Bruce

RE: MEETING with Mike Gottlieb

Protocol of possible questions:

1. What is the area of research which is most crucial right now?

Refer to Gottlieb's letter of December.

Who is currently paying for this crucial research?

Where is there a demonstrable lack of funding for such research--
and is there a chance that either government or industry money
will respond?

2. What kind of money is currently available for support for the suffering?

Is this a more reasonable place for private money to go?

3. Alternative modalities. Talk about the Rosenthal/Lerner proposal?

4. Series of questions for him about AmFAR.

1. Board contributions? Who and how much?

2. Decision-making about the grants AmFAR is going to make:

Who is going to make the grants--what is the adjudication
process?

Could AmFar serve as the pass-through for a restricted con-
tribution for a pre-determined project need?

5. Hospice care delivery. What science is currently available or in
development for hospice care? Could hospice research be a useful
use of private money? Other money?

CALIFORNIA AIDS PROJECT
AIDS ADVISORY COMMITTEE
MEETING MINUTES
October 12, 1984

The AIDS Advisory Committee met on October 12, 1984 at the State Building in San Francisco (350 McAllister). The agenda included two major topics:

- 1) Funding of new and continuing AIDS contracts, and
- 2) Discussion of how emergency medical crisis funds may be sought.

Committee Members Present

Bruce Decker, Chairman
Michael Roth, M.D., Vice-Chairman
Richard Hamilton, M.D.
William Filante, M.D.

Sal Rosselli
Stan Hadden
Michael Gottlieb, M.D.
James Chin, M.D.

Committee Members Absent

Bill Krause

DHS Staff Present

D. L. Gunter, Chief, VD Control Program
Jim Felten
Irena Heindl, M.D.

Levi Kamel, Ph.D.
Kenneth Brock, MSW
Steve Foresberg, Office of
Legislative Liaison

I. Funding of New and Continuing Contracts

The breakdown of the \$1 million general fund allocation for AIDS in FY 1984-85 was approved by the Director as follows:

\$ 150,000	Surveillance/Epidemiology
75,000	Laboratory Services
37,500	Operating Expense (travel, data processing, printing, general expense)
737,500	Information/Education Contracts
<u>\$1,000,000</u>	TOTAL BUDGET

Of the \$737,500 for I & E contracts, \$414,000 had previously been committed to continue selected FY 1983-84 contracts. The remaining monies, plus a small amount of contract savings, amount to approximately \$328,000.

Twelve proposals were received for a total dollar amount of \$724,496.

Recommendations were made to fund five new contractors and to expand services of four existing projects. A listing of all contracts funded to date is attached.

Recommendations for specific staff attention/follow-up were as follows:

1. The two major Los Angeles contractors, AIDS Project L.A. and the Gay and Lesbian Community Services Center, submitted proposals which would combine efforts to provide a comprehensive outreach program to high-risk populations.

The Committee recognized the specific different areas of expertise of these two organizations and the need for them to closely cooperate. It was decided to have State staff closely monitor this cooperative effort to ensure a functional and effective project.

2. A motion was passed for Doctor Chin to use the weight of the Advisory Committee to influence the Los Angeles Board of Supervisors via the Health Department to recognize the serious proportions of the AIDS epidemic in this community. A time limit should be indicated, and if no positive action can be documented, the Board should be approached directly to provide support for the AIDS problem.
3. Although the Center, in Long Beach, was not recommended for funding at this time, staff was requested to ensure that Long Beach high-risk populations were served by the Los Angeles contractors. Also, staff was asked to prepare a letter to the Center requesting them to restructure their proposal for consideration if supplemental funds were to become available later.
4. A minimal amount was recommended to initiate a women and AIDS pilot project within the San Francisco AIDS Foundation. A motion was passed urging staff to foster a cooperative arrangement between S.F. AIDS Foundation and Operation Concern, whose proposal for women's outreach was not funded. Operation Concern should be encouraged to work with S.F. AIDS Foundation for a mutual proposal for a later funding period.
5. An I.V. drug abuser project at the Haight Ashbury Clinic was felt to be important but not a high priority, due to low AIDS morbidity in this population. Staff was requested to closely monitor the small contract recommended for this organization to ensure an adequate methodology is used to reach the I.V. drug abuser.
6. While not recommending funds for a northern California hemophiliac program at Alta Bates hospital, staff was requested to encourage coordination of activities among statewide facilities serving the hemophiliac population.
7. The importance of the Pacific Center and its newer outreach activities in light of the growing morbidity in East Bay counties was recognized. The cut in requested amount was accepted on condition that if more money becomes available, the Center be considered as having high priority for additional monies.

8. Four new contracts, Desert AIDS Project (Riverside), Sacramento AIDS Foundation, River Community Services (Sonoma), and Gay United Services (Fresno), were considered as representing important underserved areas deserving seed money for information/education in their respective communities. It was suggested that in the future the different County Boards of Supervisors be encouraged by the above organizations to put up additional money toward overcoming the AIDS problem in their areas.
9. The Committee recommended that staff clearly note any limitations that will be placed on future RFP's so that contactors will avoid requesting funds for these items, ie. administrative costs, limitations on salary levels, benefits, milage, etc.
10. Staff was commended for the quality of and amount of time spent in evaluating each proposal and presenting the results to the Committee.

II. EMERGENCY MEDICAL FUNDS

The Committee was in agreement that additional funding was needed to continue the fight against AIDS. A motion was made to recommend to the Director that funds be sought from the State's Emergency Fund through a legislatively authored bill. Eight areas of need were identified for future AIDS funding:

Immediate Needs

1. Information/Education - To increase efforts in underserved categories of activity and underserved locations.
2. Laboratory Services.
3. Surveillance and follow-up - To enlarge field operations of epidemiologic investigations, health care provider training, liaison activities with medical facilities; assistance for monitoring of AIDS contractors.
4. Increased AIDS program staffing levels to accomplish the above activities, recognizing that much of staff time has been taken away from critical venereal disease control activities.

Long Term Needs

1. Medical/Social services for person with AIDS.
2. Added research monies for AIDS. Advisory Committee should work with special Task Force on AIDS to determine priority areas.
3. Establishment of regional Medical Testing and Evaluation Centers using facilities already providing expertise and by expanding capabilities of other facilities as needs arise.
4. Increased Administrative support for Social Services.

Staff was requested to provide a written needs assessment for Short Term items # 2, 3, 4.

A planning meeting to further develop the above Needs Statement is scheduled for November 9, 1984 in Sacramento, 2:00 p.m. - 5:00 p.m.

CALIFORNIA AIDS PROJECT
CONTRACT SUMMARY

FY 1983/84 -
FY 1984/85

CONTRACTOR	AMOUNT FUNDED 1983/84	AMOUNT CONTINUED FUNDING 1984/85	RECOMMENDED NEW FUNDING 1984/85	TOTAL FUNDING (2 yrs.)
1. AIDS Project, Los Angeles	\$ 90,000	\$ 41,386	\$ 122,448	\$253,834
2. Gay/Lesbian CSC, Los Angeles	60,000	29,189	54,732	143,921
3. San Francisco AIDS Project	71,675	60,388	40,001	172,064
4. Pacific Center - Alameda	28,022	39,419	13,841	81,282
5. Santa Clara County H.D.	37,545	52,905	—	90,450
6. Santa Barbara County H.D.	15,000	29,724	—	44,724
7. Long Beach H.D.	15,000	21,410	—	36,410
8. Orange County H.D.	17,985	—	—	17,985
9. San Diego County H.D.	17,012	22,509	—	39,521
10. San Diego AIDS Project	28,000	39,750	—	67,750
11. Gay/Lesbian CSC, Orange	23,500	50,245	—	73,745
12. Orthopaedic Hospital, L.A.	12,000	21,877	—	33,877
13. Shanti, San Francisco	24,000	—	—	24,000
14. Desert AIDS Project-Riverside	—	—	24,813	24,813
15. Sacramento AIDS Foundation	—	—	19,959	19,959
16. River Comm. Svcs. - Sonoma	—	—	22,000	22,000
17. Gay United Services - Fresno	—	—	20,000	20,000
18. Haight Ashbury - San Francisco	—	—	10,000	10,000
	—	—	—	—
	—	—	—	—
Total	\$439,739	\$408,802*	\$327,794	\$1,176,335

*\$6,000 Salary savings added
to new funding.

Mr. Bruce B. Decker
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file

The AIDS Comprehensive Statewide Plan is in preparation by our office. We are not planning to circulate drafts of the Plan prior to its projected release date of October 31, 1985. We are, however, very interested in obtaining recommendations on the Plan from your committee and other interested parties. We have prepared an outline of the statewide plan, regarding which your comments are eagerly sought.

Thank you.

Sincerely,

Original Signed By
Stanley Cubanski

Kenneth W. Kizer, M.D., M.P.H.
Director

cc: Michael Roth, M.D., Vice-Chairman
James Chin, M.D.
Honorable William J. Filante, M.D.
Michael Gottlieb, M.D.
Honorable Stan Hadden
Richard R. Hamilton, M.D.
Richard Pabich
Sal Roselli
Members of State AIDS Advisory
Committee

Donald O. Lyman, M.D., Chief
Preventive Medical Services
Division

Robert E. Anderson, M.D., Chief
AIDS Program

D.L. Gunter, Chief
Sexually Transmitted Disease
Section

AIDS ADVISORY COMMITTEE

Meeting Minutes

November 9, 1984

The AIDS Advisory Committee met on November 9, 1984 at the State Capitol Building, Room 3191, in Sacramento.

Three keynote speakers were heard:

- 1) Marcus Conant, M.D.
- 2) Robert Anderson, M.D.
- 3) Thomas Coates, Ph.D.

The following agenda items were discussed:

- I. Discussion of anticipated needs in:
 - A. Information and education.
 - B. Laboratory.
 - C. Surveillance/epidemiology.
 - D. Staffing levels.
- II. Discussion of emergency funding - process.
- III. Confidentiality of AIDS information.
- IV. Development of FY 1985-86 AIDS Program proposals.

COMMITTEE MEMBERS PRESENT

Bruce Decker, Chairman
Michael Roth, M.D., Vice-Chairman
Richard Hamilton, M.D.
William Filante, M.D.

Stan Hadden
Michael Gottlieb, M.D.
James Chin, M.D.

COMMITTEE MEMBERS ABSENT

Sal Rosselli
Bill Kraus

DEPARTMENT OF HEALTH SERVICES STAFF PRESENT

D.L. Gunter
Tom Ault
Jim Felten
Judith Shepard

Augie Detres
G.W. Levi Kamel, Ph.D.
Kenneth Brock, MSW
Steve Foresberg, Office of
Legislative Liaison

COMMENTS

Marcus Conant, M.D., recognized authority on Acquired Immune Deficiency Syndrome (AIDS), was the first out of three speakers to give a presentation.

The following is an abstract of Dr. Conant's presentation:

"Ladies and gentlemen, I come bearing more bad news, with the prospects of worst news to come. As you know, we have been tracing this epidemic since 1981 and the number of cases have continued to increase at an exponential rate."

Dr. Conant continued his presentation covering problems with doctors not reporting, statistics, diagnostic and treatment costs for AIDS patients, epidemiology, surveillance, AIDS education, psychosocial aspects, and confidentiality.

"We must develop a strong disease surveillance, since an increasing number of physicians are openly choosing not to report AIDS cases. Even so, the number of cases of AIDS being reported are doubling every nine months."

In 1981, San Francisco had 24 cases of AIDS. Since October 1984, there are 780. At this rate, by the end of 1985, there will be 1,700 cases, by 1986 over 6,000, and by 1987 over 16,000 cases of AIDS in San Francisco. In 2-1/2 years, the State of California will have 17,000 cases of AIDS. In January of 1984, one new case per day was being reported and we then predicted that by the end of this year there would be two new cases per day being reported, there are now two cases per day being reported. By this time next year, there will be two deaths per day and four new cases per day reported.

Last night there were 50 patients in San Francisco hospitals. This time next year there will be at least 100 patients in San Francisco hospitals. If the rate of cases continues to double every nine months, then 2-1/2 years from today there will be a need for 500 hospital beds in the city of San Francisco. As for California, if last night there were 102 patients with AIDS in hospitals, then in 2-1/2 years we will need 1,000 hospital beds. Therefore, in 2-1/2 years there will be a need to have additional facilities to treat and house AIDS patients. If we are thinking of opening major regional hospitals to provide care we should begin the planning right now, and not wait for the impending catastrophe."

Recommended course of action in need of funds:

1. State to work with the areas throughout California that are in need of developing educational programs.
2. Develop an efficient and accurate active surveillance State program which would cover areas throughout California being affected by AIDS. The Department of Health Services needs to know how many actual cases there are in counties such as Bakersfield, Fresno, etc.

3. Need to plan for regional treatment centers right now, and not wait until the number of AIDS patients reaches an unmanageable number.
4. Need to identify physicians, hospitals, and psychosocial facilities willing to treat AIDS patients outside of Los Angeles and San Francisco while we are developing the regional treatment centers.
5. Need to establish Medi-Cal supplemental funds for AIDS patients so that hospitals will not turn patients away. Hospitals are becoming increasingly concerned about Medi-Cal not covering all expenses.

The second speaker was Robert Anderson, M.D., who is heavily involved in epidemiological studies in San Francisco. One of his current studies is a prospective study in households of AIDS patients to determine other possible risk factors. The following is an abstract of Dr. Anderson's presentation:

"Epidemiologic data from Africa is indicating heterosexual spread of disease including spread by female prostitutes. It is becoming increasingly clear to us from our research that between five and ten percent of homosexually active males have had sex with females in San Francisco.

The basic tools to monitor this disease are available but have yet to be seriously applied. Public health departments lack the necessary manpower and laboratory facilities to undertake screening and tracing of sexual contacts.

We need to have a high level of credibility pertaining to confidentiality within the gay community in order to successfully implement and maintain successful surveillance and epidemiological programs which may uncover routes of transmission and identify new at-risk groups before they suffer the tragedy that has befallen the gay community in this state. The long incubation period suggested that we should not wait for the disease to enter other risk groups, we should go forward with research surveillance, epidemiology, and education in order to minimize the impact on the at-risk groups and not jeopardize other groups."

The third speaker was Thomas Coates, Ph.D., from the University of California, San Francisco and in private clinical practice. Dr. Coates spoke on his research studying the psychological impact of AIDS on the general and gay population:

"We should acknowledge that positive changes in behavior have been substantial since this is confirmed by at least two independent and credible surveys in San Francisco. The gay community is prac-

-4-

ticing more safe sex then ever before. The majority have proven to be knowledgeable in what is known about AIDS and the transmission of the AIDS virus. According to studies, gay men have not substituted high-risk sex practices with safe sex practice, instead, there is more abstinence in community.

Public health education should include more than printing and distributing pamphlets. Public health education has become a sophisticated blend of medical and behavior sciences.

Therefore, I am recommending the following activities:

1. Surveillance of behavior throughout the state.
 2. Continued study and analysis of the factors related to high and low risk sexual activity. Perhaps with creation of sub-committee to coordinate available resources and direct a statewide program in the development of new resources and approaches.
 3. Translation of these programs into effective health education programs.
 4. To study what the HTLV III virus positive antibody test means before it is applied publicly, since many community leaders have already expressed concern over the probable discrimination toward persons that are HTLV III positive.
 5. Continued effective education for health providers and general public."
- I. The need for additional resources for Information and Education activities was expressed by Bruce Decker. A presentation was given by Jim Felten regarding the need for continued surveillance, epidemiology, and laboratory support activities. Written justifications (attached) were distributed.
- II. The following budget recommendations for emergency funding of AIDS were suggested to the Advisory Committee by Bruce Decker:

\$ 650,000	(education/information)
100,000	(laboratory)
150,000	(surveillance/field operations)
<u>100,000</u>	(staffing)
\$1,000,000	TOTAL IN EMERGENCY FUNDS

Bruce Decker agreed with Lillis Stephens, President of the Hemophilia Association, that hemophilia organizations should be considered for emergency funding.

Discussion followed and it was suggested that the committee submit the above figures to the legislature as an emergency funding measure. The recommendation was passed unanimously.

- III. Dr. Hamilton presented a draft resolution, regarding confidentiality of AIDS victims, to the Committee for discussion (attached).

There is a concern in the Gay community that the confidentiality of information is not protected and that information will be available to employees and insurance companies. It was agreed that this is more a perceived fear than an actual one.

The Advisory Committee made a motion to Dr. Chin that he work with attorneys to ascertain the aspects of confidentiality that are already in place (or recommended) for all AIDS research projects funded by the State at any level. Discussion followed and the motion was passed unanimously.

- IV. The next Advisory Committee meeting was scheduled for Friday, December 14, 1984 in Los Angeles to discuss the development of FY 1985-86 priorities for AIDS programs in California. Bruce Decker has since rescheduled the meeting to be held in Sacramento.



HOSPITALS AND CLINICS

SAN FRANCISCO, CALIFORNIA 94143

RECOMMENDATIONS TO THE AIDS ADVISORY COMMITTEE

by Marcus A. Conant, M.D.

Director, AIDS Clinical Research Center
University of California - San Francisco

1. EDUCATION

In major metropolitan areas, public education programs directed at high risk populations are helping to encourage behavioral changes necessary to reduce the spread of AIDS. These efforts must be expanded and professionalized. New efforts must also be undertaken in areas where AIDS is not yet a major public health problem but is likely to become one.

The State should make funds available to contract with media and public education professionals to develop prototype educational materials, such as television and radio spots, video presentations, brochures, mailings, press kits and outdoor advertising. The prototypes would be made available to local health agencies and organizations for use in their communities.

2. PLANNING

The State should make funds available to the Department of Health to undertake an epidemiological study to determine the actual number of current cases and to project the number of AIDS cases likely in the next two to five years, so that contingency plans are developed to cope with the projected number of cases in each community. To make up for underreporting of AIDS cases, this study will require active case-finding.

The Task Force should seek funding for a study of the feasibility of and need for the establishment of regional health care facilities for AIDS treatment, research and patient support.

3. RESOURCE IDENTIFICATION

State funds should be made available to assist the

Department of Health in identifying those hospitals in California which have had experience with caring for AIDS patients, and identify at each hospital individuals who are expert in evaluating and treating pneumocystis pneumonia, Kaposi's sarcoma and opportunistic infections. Further, each hospital should identify someone in social services who is comfortable working with gay patients and their families, and who has the resources to help patients find emotional and financial support.

4. MEDICAL COSTS

The AIDS Task Force should request from the Department of Health a detailed survey of the actual costs to the Medi-Cal program for patients diagnosed with AIDS, in order to determine whether the level of Medi-Cal reimbursement is high enough that private hospitals are not discouraged from providing care for these patients.

5. RESEARCH

The AIDS Task Force should monitor the research proposals submitted for funding to the University of California Task Force on AIDS and should recommend increased research funding to the State Legislature if worthy research projects are not being pursued due to lack of resources.

Further, the Task Force should seek stronger procedural or legislative protections of confidentiality in AIDS research and treatment, in order to respect personal privacy and to insure that essential research is not hindered.

FOR IMMEDIATE RELEASE

Leon McKusick, MS
Thomas J. Coates, Ph.D.
Marcus Conant, MD
Stephen Morin, Ph.D.

NOVEMBER 1, 1984
University of California
AIDS Behavioral Research Project
4627 17th Street
San Francisco, California 94117
(415)731-7468

Longitudinal Change in Continuing Respondents

In November 1983 we surveyed men in four sampling locations: bathhouses, bars, advertising for men who had not used bathhouses and bars, and committed primary relationships (Couple sample drawn May 1983). 655 men from these four groupings responded to the November 1983 questionnaire. Of these men, 557 volunteered to be re-contacted in May 1984 for another measure of their sexual behavior and attitudes. 454 of these volunteers returned the May questionnaire.

An analysis of the major demographic variables indicated that our longitudinal sampling procedure was not biased by attrition.

In our November questionnaire we gathered retrospective data on relationship status and sexual activity in November 1982. Table 1 describes changes in numbers of sexual partners and frequency of specific sexual practices both with primary partners and with secondary or anonymous sexual contacts.

Sample and Type of Activity	Reference Period		
	November 1982 (retrospective)	November 1983 (current)	May 1984 (current)
PERSONS IN RELATIONSHIPS IN NOV83 and MAY84			
1. Average number of times had sex with primary partner in last month	10.8	9.7	8.5
2. Average number of times within last month with primary partner:			
Receptive anal intercourse w/o condom	3.3	2.6	2.2
Swallow semen	4.4	3.2	2.5
Mutual masturbation	4.4	5.0	4.7

Sample and Type of Activity	November 1982 (retrospective)	November 1983 (current)	May 1984 (current)
PERSONS WHO WERE NOT IN RELATIONSHIPS OR HAD SEX OUTSIDE A RELATIONSHIP IN BOTH NOV83 AND MAY84			
1. Average number of partners last month	6.3	4.9	3.9
2. Average number of times last month respond- ent engaged in _____ with new or secondary partners:			
Receptive anal intercourse without condom	1.9	1.3	.7
Swallowing semen	2.8	1.1	.7
Mutual masturbation	2.5	2.5	2.1
3. Number of times respond- ent went to a bathhouse	2.4	1.5	.6

Table 1 demonstrates that significant changes have occurred in all behaviors considered to be high risk over the past 1½ years. Men are having less high risk sex inside primary relationships, fewer numbers of sexual partners, and a lower frequency of high risk sex with secondary or anonymous contacts. What is interesting to note is that the total level of sexual activity has diminished, not just specific sexual acts. Although mutual masturbation, a low risk activity, has remained relatively stable, it has not increased significantly. This suggests that men are less likely to substitute low risk sex for high risk sex, but may be more likely to inhibit sexual activity altogether, even in a primary relationship, in response to the epidemic.

The level of monogamy in existing relationships has remained stable, and the proportion of men in relationships continues to remain relatively the same over time. Although this may be due in part to sampling bias, it indicates that beginning and maintaining a primary relationship has not become an adaptive response to AIDS threat, at least by May 1984.

Attendance at bathhouses has decreased significantly over the period of measure, as well as numbers of sexual partners encountered in bathhouses.

Analysis of Health Beliefs and AIDS Risk Reduction (May 1984)

In order to assist with AIDS prevention efforts, we have developed a model to be used in AIDS education efforts. The model addresses psychological variables that may play an important part in determining whether or not a person engages in low risk behavior. The model has the following points:

- 1) Perceived Threat: A belief that one is potentially at risk of exposure to AIDS, coupled with a firm belief that this is an outcome to be feared.
(Example: "I am fearful of getting AIDS.")
- 2) Response Efficacy: A belief that AIDS can be avoided by taking specific protective actions.
(Example: "AIDS can be prevented.")
- 3) Personal Efficacy: A belief that one is capable of taking recommended action that would lessen the risk of exposure to AIDS.
(Example: "I am able to refrain from having anonymous sex.")
- 4) Skills Attainment: Social contracting skills necessary to negotiate low-risk sexual behaviors.
(Example: "I am comfortable discussing sexual limits with a potential partner.")
- 5) Peer Support: Social support for adopting patterns of low-risk sexual behavior.
(Example: "I am likely to get alot of support from others for being cautious about sexual behavior.")

Questionnaire items were developed to assess each of the five variables. In addition, a measure of self esteem was administered (Rosenburg, 1965). A measure of agreement with specific health guidelines (i.e. "that swallowing semen is a high risk activity") was also placed in the questionnaire. Statistical analysis was then performed to see the extent to which each of these constructs were related to an individual's overall sexual risk behavior. Risk levels were assigned to behaviors based on their probable risk of disease transmission. Each risk activity was multiplied with the number of times the individual reported doing this behavior in the past month with new or secondary partners. The sum represents the individual's risk score.

The four groups varied considerably on risk score, perceived threat and personal efficacy. In terms of overall risk the bath sample continued to be considerably higher than the other groups. The no bar/no bath group was by far the lowest in terms of their risk score.

Perceived threat differed significantly across groups. The lowest perceived threat was in the bath group. The bath and bar groups were lower in personal efficacy than the other two groups. The couples group was higher in self esteem than the other groups.

To further understand which aspects of health belief and self esteem most strongly predicts lowering risk, a regression was performed on risk score.

Personal efficacy and strength of belief in health guidelines accounted for most of the variance in risk score.

The respondents were then divided into three groups according to their risk scores. In the low risk group (zero risk score in sample month), 166 of the respondents were monogamous, 65 of the respondents were celibate, and 40 of the respondents engaged in totally safe sex (total= 271). In the moderate risk group (risk score less than median) the total respondents were 258. In the high risk group (risk score greater than median) the total respondents were 257.

Again, personal efficacy was shown to differ significantly among risk groups with greater personal efficacy associated with lower risk. Skills attainment was also found to be significantly related to lower risk.

Looking at specific questionnaire items, the low risk group was the most likely to believe that saliva can transmit AIDS and that someone could be capable of transmitting AIDS while appearing very healthy.

The moderate risk group was most likely to endorse health guidelines such as the belief that people should reduce the number of partners, and use condoms. The moderate risk group was the least likely to be satisfied with their sex life.

The high risk group was the most likely to believe that one can relax about risk reduction because a vaccine will be available soon, and that they had already been exposed to AIDS and had successfully fought it off. This group was also the most fearful that they could transmit AIDS.

Across the risk groups a correlation was found between risk reduction and a belief that life has changed and we have to adjust to AIDS. There was also high agreement with a statement that AIDS can be transmitted in one sexual contact, which was also correlated with lower risk.

These data could be useful in understanding what aspects of gay men's psychology and health belief are most relevant to risk reduction and those aspects which still need targetting by primary and secondary prevention efforts.

A G E N D A

AIDS ADVISORY COMMITTEE MEETING
CALIFORNIA STATE CAPITOL
ROOM 2040
SACRAMENTO, CALIFORNIA

NOVEMBER 9, 1984

- 2:00 P.M. I. WELCOME AND INTRODUCTIONS Bruce Decker, Chairman
- A. STATISTICAL INCREASES Marcus Conant, M.D.
 IN AIDS
- B. HEALTHY GAY POPULATION Robert Anderson, M.D.
 STUDY
- C. PSYCHOLOGICAL IMPACT OF Thomas Coates, ~~M.D.~~ *Ph.D.*
 AIDS ON GENERAL AND GAY
 POPULATIONS.
- 3:00 P.M. II. DISCUSSION OF ANTICIPATED NEEDS IN:
- A. INFORMATION AND EDUCATION
- B. LABORATORY
- C. SURVEILLANCE/EPIDEMIOLOGY
- D. STAFFING LEVELS
- III. DISCUSSION OF EMERGENCY FUNDING - PROCESS
- IV. CONFIDENTIALITY OF AIDS INFORMATION
- V. DEVELOPMENT OF FY 85-86 AIDS PROGRAM PROPOSALS
- 5:00 P.M. VI. ADJOURNMENT - PLANS FOR NEXT MEETING

COUNTY OF LOS ANGELES
ESTIMATED AIDS EXPENDITURE
FOR FISCAL YEAR 1983-84

<u>DEPT. OF HEALTH SERVICES</u>	<u>INPATIENT</u>	<u>OUTPATIENT</u>	<u>TOTAL</u>
LAC/USC Medical Center	\$ 2,100,000	\$ 150,000	\$ 2,250,000
Harbor/UCLA Medical Center	272,614	5,760	278,374
MLK, Jr./Drew Medical Center	50,000	-0-	50,000
Rancho Los Amigos Med. Ctr.	-0-	-0-	-0-
Olive View Medical Center	301,000	8,000	309,000
Mira Loma Medical Center	<u>-0-</u>	<u>-0-</u>	<u>-0-</u>
SUBTOTAL	\$ 2,723,614	\$ 163,760	\$ 2,887,374
 Ambulatory Care Services	\$ —	\$ 900	\$ 900
Public Health Programs	--	312,983	312,983
Antelope Valley Rehab. Ctr.	--	-0-	-0-
Mental Health	--	-0-	-0-
Alcohol and Drug Abuse	<u>—</u>	<u>7,587</u>	<u>7,587</u>
SUBTOTAL	\$ —	\$ 321,470	\$ 321,470
TOTAL - DEPT. OF HEALTH SERVICES	\$ 2,723,614	\$ 485,230	\$ 3,208,844

OTHER COUNTY DEPT.

FEMA	\$ 51,000
Community Development - Block Grant	<u>5,000</u>
TOTAL - OTHER COUNTY DEPT.	\$ <u>56,000</u>
NET TOTAL - COUNTY OF LOS ANGELES	\$ <u>3,264,844</u>

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From the office of SUPERVISOR ED EDELMAN/Third District

Contact: Jami Warner • John Stodder / 974-3333

July 18, 1984

EDELMAN ANNOUNCES \$35,549 GRANT TO AIDS PROJECT

Supervisor Ed Edelman announced that the County Mental Health Department has awarded a contract of \$35,549 to the AIDS Project/Los Angeles to support mental health and psychological services to persons with AIDS (Acquired Immune Deficiency Syndrome).

"This \$35,549 County grant is particularly significant because it will add professional staff to supplement the heroic efforts of the volunteers and current staff at the AIDS Project" Edelman said. The funding was included in the County's 1984-85 budget as a result of inquiries by Supervisor Edelman about the level of Mental Health resources being devoted to services for persons with AIDS. During the Board of Supervisors budget deliberations, Edelman proposed that the Mental Health Department provide \$90,000 for AIDS-related services.

"In Los Angeles, much of the direct support for persons with AIDS has been provided by volunteer agencies," Edelman said. "But the continuing seriousness of the AIDS crisis and the ever-increasing number of patients present the real potential for burn-out among individual volunteers and agencies," he added.

"That is why this kind of direct support from the County Mental Health Department to the AIDS Project is so important," Edelman said. "It can provide additional paid staff to help handle the increasing demands on the existing staff and volunteers at the AIDS Project," Edelman concluded.

According to Bill Misenhimer, Executive Director of the AIDS Project, the County grant will be used to hire a licensed clinical social worker.

In addition to the \$35,549 grant to the AIDS Project, the County Mental Health Department will be providing psychological services to persons with AIDS through existing County programs in the Hollywood area. At a minimum, these services will include \$18,000 in Mental Health staff time.

APLA -- CALIFORNIA AIDS PROJECT

PROGRAM FUNDING ASSUMPTIONS AND CONCLUSIONS

ASSUMPTION	APLA	CAP
"This is not a 'gay community' problem in CA."	agree	disagree *
"The straight community is not a source of funding"	agree	disagree
"The gay community as a funding source has been drained"	agree	strongly disagree
"The gay community will not support APLA because it does not want labelled a gay organization."	strongly disagree	would agree that this possibility could be studied in W. Hollywood, etc.

* both agree that AIDS is also a public health issue.

→ CAP Conclusion: Private sources of funding can be developed.

→ APLA Conclusion: Private sources of funding can not readily be developed.

AIDS PROJECT LOS ANGELES

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937 NORTH COLE AVENUE • SUITE 3 • LOS ANGELES CA • 90038

(213) 871-1284

FOR IMMEDIATE RELEASE

CONTACT: Jim Kleckner (213) 380-3786

AIDS Project receives
County funds for emergency
food and shelter services

LOS ANGELES (September 20, 1983) - The AIDS Project/Los Angeles has received a grant of \$51,701 from the Los Angeles County Board of Supervisors. Funds will be used to provide emergency food and shelter services for persons with AIDS (Acquired Immune Deficiency Syndrome) and related illnesses.

This is the first such grant in the County of Los Angeles and the first in the short history of the AIDS Project. Ed Slough, newly-appointed Executive Director for the Project, coordinated the preparation of the grant proposal. A non-profit organization, the Project provides support services for persons with AIDS, community education and funding for AIDS research.

"These funds will enable us to respond to an increasing need for emergency shelter," commented Dr. Joel Weisman, Co-Chair of the Project's Board of Directors. "Many of the existing emergency shelters have refused to house persons with AIDS and others have been rejected by roommates, partners and family. Some hotel and apartment owners are refusing to rent to persons with AIDS or have evicted them."

Services will be targeted to impoverished, homeless and/or low-income persons who have been diagnosed for AIDS and related illnesses. The grant will enable the Project to provide the following:

- Establish an emergency shelter capable of feeding and housing six persons with AIDS.
- Expand the Project's existing feeding program to purchase and deliver groceries to the homes of 45 people.
- Provide emergency lodging in a hotel (through a voucher system) for an average of five days each to 30 people.
- Provide on-time payment of rent for 30 people who have received eviction notices so they do not become homeless
- Provide one-time payment of mortgages for six people who have received lien or foreclosure notices so they do not become homeless.

The bulk of the funding \$38,606, came from Supervisor Ed Edelman (Third District) with the remainder split between Supervisors Pete Schabarum (First District), Kenneth Hahn (Second District) and Michael Antonovich (Fifth District).

According to Supervisor Edelman, "I am particularly pleased about this grant because I know that APLA can use the funds immediately to help persons with AIDS meet their basic food and shelter needs."

For additional information about the available funds and how to apply, contact Coleen Johnson at the Project Office (213) 871-1284.



Tom R

From the office of SUPERVISOR ED EDELMAN/Third District

Contact: Jami Warner • John Stodder / 974-3333

December 6, 1983

EDELMAN ANNOUNCES AIDS STATUS IN LOS ANGELES COUNTY

Supervisor Ed Edelman released a County Health Department report on the status of AIDS (Acquired Immune Deficiency Syndrome) in Los Angeles County which has confirmed 233 cases as of November 30 of this year.

In addition, the report states that 100 of the 233 cases have resulted in the patient's death, a 42.9% mortality rate. Another 65 cases are now under investigation in the County.

"As the incidence of AIDS continues to increase, we must do everything possible to help solve this tragic medical mystery," Edelman said. "The Department of Health Services is currently working with agencies involved in AIDS investigation and education, including the AIDS Project-Los Angeles and the Gay and Lesbian Community Services Center," he added.

Edelman recently announced that the Centers for Disease Control (CDC) approved Los Angeles County's proposal for \$107,590 additional funding to support AIDS monitoring and data collection activities.

"The primary objective of this program is to develop and maintain a central registry of epidemiologic and clinical information," Edelman said. "This will allow for rapid retrieval of case information and updates on the status of AIDS locally," he added.

AIDS STATUS
December 6, 1983
Page Two

"This project is of particular importance because it will allow for improved monitoring and data collection activities in the determination of incidence trends and risk factors associated with AIDS," Edelman said. "It will also provide opportunities for future studies of AIDS and related disorders," he added.

In addition to its monitoring and direct case activities, the County Health Department sponsors a monthly information exchange for all local health and support agencies treating persons with AIDS. "Efforts like these help to integrate the local public and private efforts and provide direct communication between the agencies," Edelman said. "Cooperation among all the key agencies and local groups will help avoid any unnecessary fear or confusion, and will help us to provide real assistance to persons with AIDS," he added.

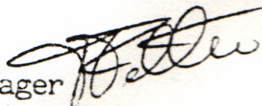
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Memorandum

To : AIDS Advisory Committee Members

Date : November 15, 1984

Subject: Supplement to November 9,
1984 AIDS Advisory Committee
Meeting Minutes

From : Jim Felten, Manager 
Administrative Services
VD Control Program

Because of the crowded agenda at Friday's Advisory Committee meeting, Department of Health Services staff was unable to report on the progress of committee recommendations from the previous meeting. Those recommendations, as well as staff follow-up activities, are as follows:

1. Close monitoring of the development of the L.A. CARES project. Ken Brock is assigned to this project. He has met with the Executive Directors of both the Gay and Lesbian Community Services Center and AIDS Project/Los Angeles to define roles, clarify lines of communication, and help plan the initial stages of the project. Ken's active involvement has been welcomed by both organizations, including his participation on the L.A. CARES management team. Ken and other AIDS staff are sharing information and assistance regularly, and will have input into the selection of the L.A. CARES project coordinator. Ken meets monthly with the management team and communicates telephonically on an ongoing basis. This gives the Department of Health Services a role in the day-to-day operation of L.A. CARES.
2. Presentation on the AIDS epidemic to the Los Angeles Board of Supervisors. James Chin, M.D. will approach Martin Finn, M.D., Los Angeles Health Department Medical Officer, about the prospects for implementing this activity.
3. Letter to The Center, Long Beach. The Advisory Committee asked that a letter be sent to the Executive Director of The Center, Long Beach, to explain that his proposal for AIDS funding could not be approved at this time. A letter was sent offering assistance from the L.A. CARES project and urging county-wide cooperation (see attached letter).
4. Cooperation between Operation Concern and the San Francisco AIDS Foundation. AIDS staff initiated both verbal and written communication to Carole Migden, Director of Operation Concern, urging interagency coordination for the delivery of AIDS-related services to women. In addition, Lyn Paleo, coordinator of State funded projects at the San Francisco AIDS Foundation, is offering her cooperation by contacting Operation Concern staff and management (see attached letter).

5. The Haight-Ashbury IV Drug Project. Levi Kamel has met with the project coordinator and finalized the contract and budget agreement. Ongoing telephonic communication, monthly meetings, and monthly reports, as recommended by the Advisory Committee, are part of the monitoring process.
6. Development of a statewide plan to deliver AIDS educational services to the hemophilia community. Levi Kamel is meeting with several representatives of the hemophilia community to discuss strategies for implementing AIDS educational services to hemophiliacs. The goal of a final plan is to ensure that all California hemophiliacs and their families have access to AIDS education services. A final plan will be developed in time for the next funding cycle (see attached letter).
7. Improve AIDS educational services in Alameda County. AIDS staff has provided consulting activities to the Pacific Center for Human Growth, which currently provides AIDS services in Alameda County, in order to enhance the effectiveness of existing programs. In addition, the San Francisco AIDS Foundation is providing valuable consulting, resource and information sharing, and technical assistance to the Pacific Center. As a result of these efforts, Alameda County's AIDS program has improved.
8. Additional funds from counties. Several local agencies have been encouraged by State AIDS staff to seek AIDS funding at the county government level. In addition, the idea of requiring matching funds for contracts is being investigated.
9. In future RFP's, list non-fundable line items for respondents. AIDS staff will agree and finalize a non-fundable item list based on the needs and resources available at the time the next RFP is released.

Attachment
JF:kni

October 25, 1984

Michael Brown, Ph.D.
The Center, Long Beach
2025 East Tenth Street
Long Beach, CA 90804

Dear Dr. Brown:

Thank you for your proposal dated September 21, 1984, in response to our recent AIDS request for proposals. We regret that your proposal was one that could not be funded at this time.

However, the California AIDS Advisory Committee, upon reviewing your proposal and the other proposals from the Los Angeles area, has recommended that other contractors should provide your organization with AIDS educational materials to be distributed among the high-risk groups in the Long Beach area.

The coordinator of the Long Beach City Health Department AIDS Project will also be involved in the coordination of material distribution activities.

Meanwhile State AIDS Program staff are available to your organization, as we are to all AIDS related agencies in California, for information and advisement to the extent that our resources permit. Please contact one of us if you have further questions or comments.

Sincerely,



Jim Felten, Manager
Administrative Services
VD Control Program
P.O. Box 2230
Sacramento, CA 95810-2230

JF:so

October 25, 1984

Carole Migden
OPERATION CONCERN
1853 Market Street
San Francisco, CA 94103

Dear Ms. Migden:

Thank you for your proposal dated September 21, 1984, in response to our recent AIDS request for proposals. We regret that your proposal was one that could not be funded at this time.

After reviewing your proposal for a "Women and AIDS Project", the California AIDS Advisory Committee recommended that a pilot project to assess women's AIDS-related needs statewide be initiated at another agency. That agency has agreed to include OPERATION CONCERN representatives in meetings and appropriate activities during the developmental phase of a statewide plan.

Meanwhile, State AIDS Program staff are available to your organization, as we are to all AIDS-related agencies in California, for information and advisement to the extent our resources permit. Please contact one of us if you have further questions or comments.

Sincerely,


James A. Falten, Manager
Administrative Services
VD Control Program
P.O. Box 2230
Sacramento, CA 95810-2230

JAF:kni

October 25, 1984

Brad Lewis, M.D.
ALTA BATES FOUNDATION
2855 Telegraph, #603
Berkeley, CA 94705-1171

Dear Doctor Lewis:

Thank you for your proposal dated September 21, 1984, in response to our recent AIDS request for proposals. We regret that your proposal was one that could not be funded at this time.

However, the California AIDS Advisory Committee has recommended that the California AIDS Program staff to coordinate a statewide meeting of hemophilia community leaders as soon as possible. This meeting is for the purpose of developing a statewide coordinated response to the AIDS educational needs of all California hemophiliacs.

Meanwhile, State AIDS Program staff are available to your organization, as we are to all AIDS-related agencies in California, for information and advisement to the extent that our resources permit. Please contact one of us if you have further questions or comments.

Sincerely,


James A. Felten, Manager
Administrative Services
VD Control Program
P.O. Box 2230
Sacramento, CA 95810-2230

JAF:kni

NEEDS ASSESSMENT
AIDS (Acquired Immune Deficiency Syndrome)
Surveillance/Epidemiology
Fiscal Year 1985-86

Acquired Immune Deficiency Syndrome (AIDS) is a relatively new malady characterized by the contraction of formerly rare diseases such as Kaposi's Sarcoma and other "opportunistic" infections which are associated with a specific and apparently irreversible defect in cell-mediated immunity. While the etiologic agent (retro-virus HTLV-III) has been identified, there is as yet no vaccine or cure for AIDS. At the present, patients diagnosed with AIDS have experienced no restoration of the immune system.

As of October 1, 1984, 1498 cases of AIDS have been reported with 572 deaths. Of the 1498 total cases, 766 or 51% of these were reported in the last nine months. Projections by the Centers for Disease Control estimate 14,000 Californians will have contracted AIDS by 1987.

In spite of the identification of the etiologic agent of AIDS (HTLV-III) and the development of blood tests to detect exposure to the causative agent, there are still many uncertainties relating to the syndrome. The long incubation period, the unknown cofactors, the high case fatality rate, and the lack of specific interpretation of the blood tests emphasize the need for intensified surveillance and epidemiology of this syndrome.

If the projections are correct, with the number of cases doubling every six to nine months, additional resources will be needed to maintain

effective disease control measures. Currently, \$150,000 is allocated for this purpose. This amount will fund four field positions, one contract monitor and one clerk through the eight months remaining in FY 1984-85.

The four field positions are assigned to work in previously unserved areas of the state outside of Los Angeles and San Francisco. Four additional positions were originally requested to assist in the Los Angeles and San Francisco AIDS programs but funds were not made available in this fiscal year.

The following responsibilities of the AIDS Program reflect the need for continued funding to maintain the current activities and increased funding in order to expand staff levels to provide services in areas with moderate to high morbidity, throughout the state:

I. AIDS CASE REGISTRY

In order to obtain complete and timely information on all AIDS cases diagnosed in the State, the California Department of Health Services on March 23, 1983 declared AIDS cases to be a legally reportable condition under California Administrative Code Title 17, Section 2503, which pertained to the reporting of the occurrence of unusual diseases.

The State AIDS Case Registry coordinates and monitors California's reporting system. The Registry was established to strengthen the interaction and communication between the State AIDS Program, San Francisco, Los Angeles, and the Centers for Disease control. This

permits more effective investigations of blood donors to AIDS cases, low-risk cases, questionable cases, etc., and for updating case information. This information is necessary since it may provide valuable insights into the many variables associated with AIDS which will enhance our knowledge of the medical epidemiological and psychosocial aspects of the syndrome and, eventually, provide clues for its prevention and eventual eradication.

AIDS field staff are integral to the Case Registry in that they:

- 1) Obtain needed Epidemiologic information regarding AIDS patients on a continuous basis;
- 2) Clarify missing or conflicting information with private physicians and hospital staff;
- 3) Conduct follow-up investigations on patients and close associates;
- 4) Maintain active reporting mechanisms by health care providers and by utilizing other reporting systems, i.e. death certificates, T.B. reports, etc;
- 5) Ensure absolute confidentiality by local health department and other involved agencies; and,
- 6) Provide accurate and timely information regarding pertinent AIDS data to local health agencies and interested community groups.

II. SURVEILLANCE ACTIVITIES

The most pivotal program component is surveillance; the report of a case of AIDS represents the means by which future disease control processes can be initiated.

Up until now, AIDS surveillance in California has been extensive, but it has been to a great extent "passive surveillance" (i.e. receiving reports, follow-up and requests), rather than active. An expansion program in AIDS surveillance would not only include currently underserved areas; but would also permit active surveillance activities in many counties of the state. Health officials have expressed a strong need for the development of an AIDS surveillance program. In some cases, these agencies have received increasing requests from community groups to meet surveillance needs.

AIDS surveillance should therefore progress into a more active role. Key personnel in hospitals and medical laboratories throughout the State of California should be contacted regularly. These personnel would include infection control doctors and nurses, pathologists, and dermatologists. A regular program of visits would lead to more efficient reporting and a stronger surveillance base.

Active AIDS surveillance in unserved geographic areas, as well as underserved areas of California, will also demonstrate the effectiveness of community-based organizations, as well as city and

county governments, in disseminating information and education to high-risk groups, health providers, and the general public. This will enable the state to assist certain contractors dealing with information and education to direct into areas where the need exists.

Systematic surveillance activities must continue both to ensure accurate monitoring of the incidence of AIDS and as the only practical means of evaluating the efficacy of risk reduction and preventative measures.

In order to achieve an adequate system of surveillance, additional staff/and resources are needed to:

- 1) Assist and consult with local county health medical and field staff in designing, planning, and implementing active and passive surveillance systems;
- 2) Conduct visits to major medical providers, laboratories, county medical societies and military medical facilities within the top morbidity counties and, if feasible, neighboring lower morbidity areas. AIDS informational packets will be distributed and specific information will be addressed regarding the following: a) objectives of the surveillance program; b) technical information and resources for the identification of suspect opportunistic infections; c) resources for diagnostic confirmation; d) the procedure and the necessity for immediate reporting of both AIDS confirmed and suspect

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cases test results; e) procedures for assuring patient confidentiality and personal privacy; and. f) identification of a key person who will be responsible for coordinating surveillance data;

- 3) Conduct visits to private physicians who are seeing high-risk patients. (Pediatric immunologists, selected county health department personnel, infection control nurses in hospitals providing care for children and personnel in primary care clinics treating populations at increased risk for AIDS) to inform them of the need for surveillance, provide them with case definitions, and review the new AIDS Case Report form being used to report pediatric cases;
- 4) Conduct visits to hemophilia treatment centers, prison clinics or hospitals, and community organizations/clinics that see a large number of clients who are gay, who use drugs or who have hemophilia to enlist their participation in an active or passive surveillance program for AIDS.

In addition hospitals, private physicians, laboratories and other private/public health care providers not selected to participate in the active surveillance system will be contacted through periodic meetings, mailings, personal contacts, and telephone calls to provide AIDS "updates" and to remind them of the importance of reporting.

State AIDS field representatives will promote coordination and planning of AIDS information and education (especially health provider education) activities in their respective areas by active surveillance visits to health departments, hospitals, health providers and community organizations.

Quarterly feedback data will be provided by AIDS field representatives to all participating surveillance sources to promote the importance of reporting and to provide evidence that the AIDS data presented to each site is being used.

III. EPIDEMIOLOGIC ACTIVITIES

Currently, AIDS field staff attempt to interview and counsel AIDS patients who do not fall into known high-risk groups (homosexual and bisexual males, drug abusers, hemophiliacs, Haitians).

Staff also follows patients who have received blood transfusions, or donated blood and conducts epidemiologic follow-up of possible related donors and recipients.

Sex partners to AIDS patients are not routinely followed due to insufficient staffing levels; and, protocols to provide adequate referral services have also not yet been developed. Presently, these non high-risk AIDS patients are interviewed by local health department personnel with State AIDS field staff monitoring and/or reinterviewing cases that are followed by the local staff.

Ongoing studies in Orange County show that 25% of patients with AIDS Related Complex (ARC) have developed into diagnosed AIDS cases. In addition, tests done in San Francisco show that 70% of the high-risk population will have a positive antibody test for

AIDS when the test is made available.

Given the nature and potential of the AIDS epidemic, there is the need for enhanced epidemiologic intelligence; current resources do not begin to meet this need. Additional resources would provide staffing levels to conduct interviews and follow-up activities on selected AIDS cases and potential cases.

Information sought in these interviews would include the history and character of sexual partners, percutaneous drug abuse, and specifics regarding donations of blood and plasma. Additional resources would also permit more rapid follow-up of donors to AIDS patients, and obtain blood samples whenever appropriate. Staff would provide consistent and timely contacts with physicians, clinics, hospitals, and patients to determine changes in health status, such as new opportunistic infections, progression of malignancy, and death.

IV. INFORMATION AND EDUCATION ACTIVITIES

Information and Education activities are currently provided through contracts with eighteen community based organizations throughout the state. One position is funded to monitor these contracts, i.e. to provide guidance and direction and to ensure that contract objectives are properly initiated and followed.

In conjunction with their responsibilities in surveillance and

epidemiology. Field staff would work closely with local AIDS contractors to identify educational needs among health providers, high-risk groups and individuals. Field assignees would be able to assist the contractors by distributing information to health providers in the course of their surveillance visits, by referring AIDS patients, families and friends to the appropriate local AIDS organization for counseling services and by providing objective feedback to the contractor and to the AIDS contract monitor regarding the quality of their services.

In conclusion, the addition of staff and supportive resources would help to coordinate statewide AIDS efforts into a comprehensive program including surveillance, epidemiology and educational activities.

Justification for AIDS Laboratory Support for FY 1985/86
For
The Viral and Rickettsial Disease Laboratory

Partial funding of \$75,000 to the Viral and Rickettsial Disease Laboratory Section (VRDLS) of the California Department of Health Services (CDHS) for 3/4 of the FY 1984/85 has made it possible to initiate laboratory studies on AIDS-related retroviruses and on antibody tests which will help the VRDLS and the Infectious Disease Section (IDS) carry out their missions on AIDS investigation and control. It is anticipated that by the end of the FY 1984/85 the VRDL will have: (1) hired and begun the training of qualified virologist and support staff members; (2) obtained most of the necessary equipment, supplies, standard viral strains and cell cultures needed to initiate studies; (3) developed expertise in isolating and identifying AIDS-associated viruses and in assessing AIDS virus-specific antibodies; (4) established standard, written test protocols and safety procedures, for test methods available; and (5) begun training of selected local health department staff in standard laboratory methods for AIDS studies.

It is essential that this laboratory program be sustained for the full FY 1985/86 (\$100,000) in order to capitalize on the initial investment costs and utilize the training, expertise and methods which will have been developed. The needs and emphases for FY 1985/86 will be: (1) to maintain qualified staff members and further develop their expertise in working with retroviruses, (2) to distribute standard test protocols and extend bench training to qualified local public health laboratories which will be collaborating with the CDHS in AIDS studies and control; (3) to obtain additional special equipment required by rapidly changing technologic advances and improve and adapt new test procedures for the rapid, economical and accurate detection of AIDS-related viruses, viral antigens or components, and viral-specific antibodies; (4) to use these procedures in support of AIDS investigations by the IDS, local health departments, or other collaborating groups in California; and (5) to maintain up-to-date evaluations and experience with the numerous new, licensed test methods and products for AIDS studies which are expected to be developed in the next few years.

AIDS Advisory Committee

November 9, 1984

Resolution Introduced by Richard Hamilton, M.D.

Subject: Distrust of Confidentiality

Problem: Statistically valid data is difficult to acquire.

Appropriate responses to the immune deficiency crisis by local, state and federal agencies require information from or about individuals and communities affected by AIDS. This generalized data is needed to develop funding and educational priorities. Individuals being asked to contribute data are becoming increasingly reluctant to trust the ability of agencies gathering and utilizing data to maintain confidentiality. Public agency actions, such as comparing lists of people with illness to those donating blood and closing the bath houses, are further compromising trust. As this occurs it becomes increasingly difficult for investigators to compile scientifically accurate data.

- Resolution:
- 1) The AIDS Advisory Committee recommends legislation:
 - To provide protection from subpoena to principle investigators in the AIDS field similar to that provided to investigators in the field of drug and alcohol abuse.
 - To make it illegal and punishable if any research data is used in any way to restrict any individual's right to housing, employment and/or consideration for insurance coverage.
 - To require investigators to provide all human subjects a document describing in lay language the roles of the subject, research staff, funding agencies and governmental agencies in protecting personal confidentiality.
 - 2) The AIDS Advisory Committee directs the Department of Health:
 - To draft and/or organize the guidelines it uses in the handling of data from confidential sources such as AIDS research subjects and make them known more publically through press releases, public service announcements and a press conference once the above proposed legislation has been considered.
 - To clearly define to the people of California the procedures and limitations imposed by law on the access to the names of people about whom or from whom data is obtained.

AIDS ADVISORY COMMITTEE
MEETING MINUTES
December 14, 1984
State Capital, Room 2040
Sacramento

COMMITTEE MEMBERS PRESENT

Bruce Decker, Chairman
Michael Roth, M.D., Vice Chairman
Richard Hamilton, M.D.
Stan Hadden
James Chin, M.D.

COMMITTEE MEMBERS ABSENT

Michael Gottlieb, M.D.
Sal Rosselli
Bill Kraus
William Filante, M.D.

DEPARTMENT OF HEALTH SERVICES STAFF PRESENT

D.L. Gunter
Jim Felten
Steve Foresberg

STAFF REPORT - D.L. Gunter

1. Current AIDS statistics (attached). As of December 14th, over 1700 cases have been reported in the state.
2. Contract Site Reviews. All contractors have been visited with the exception of two new contractors, which are scheduled for January.
3. The proposed structure of the State AIDS program was discussed (organization chart attached). If additional positions are approved with the emergency funds, certain program functions will be expanded.
4. Federal grants to California are currently funding AIDS surveillance and epidemiology on a limited bases as follows:

Los Angeles - \$117,461 for surveillance & epidemiology + \$186,045 for blood transfusion study
San Francisco - \$144,860 for surveillance & epidemiology + \$223,007 for blood transfusion study + \$364,259 for Hepatitis B study.

California (excluding LA & SF) - \$196,996 (\$70,000 for Orange County) for surveillance & epidemiology.
5. An international conference on AIDS is scheduled next April at CDC. Doctor Gottlieb is on the agenda. Staff will attend if possible.

MOTION: Committee will recommend to DHS that staff be able to attend.

6. The Committee report to the Director, as specified in ACR 118, is due December 31, 1984. Bruce Decker and Stan Hadden have taken responsibility for the report. DHS staff are available to provide information if necessary.
7. Follow-up staff work on Committee recommendations from previous meetings was presented by Jim Felten.

BLOOD BANK REPORT - John Horrell, Brian McDonough, Paul V. Holland, M.D.
(see attached statement)

Recommendation from the blood bank representatives included:

1. Requiring that all blood/blood products be tested for AIDS.
2. Changing the State Hepatitis donor Deferral Registry to include AIDS cases without identifying those names as AIDS patients.
3. Enacting legislation to protect confidentiality of donor information.

Doctor Chin stated that the California AIDS Task Force has made recommendations (still in draft) that address the blood bank issues.

MOTION: - The Committee recognized the concerns of blood donors and recipients and will attempt to accommodate them in any proposed legislation.

FUTURE AIDS FUNDING

1. The Committee recommended \$1 million be sought in Emergency funding in their last meeting. A letter has been sent to the Director with this recommendation.
2. The AIDS Committee, as a whole, cannot be involved in drafting legislation for increased AIDS funding. The Committee's function is to advise the Director of Health Services. Committee members, however, are free to pursue the issue as individuals.
3. Request-for-Funding (RFP) draft copies were distributed. Members were asked to provide feedback/comments to staff by Monday, December 17th.

MOTION: - Bruce Decker will call the Director to request that RFP'S be distributed to potential contractors as soon as possible.

4. Doctor Chin noted that CDC is developing an RFP for states to submit proposals for Information and Education. \$1.5 million may be available nationwide.

The Chairman asked that CDC be made aware that California has developed good pilot programs in AIDS that should be considered for use in other

Doctor Roth mentioned that new fiscal policies under the Public Health Service Act will soon be making funds available for I & E. He will be persuing this issue with Congressman Roybal.

5. The Chairman stressed that more needs to be done to motivate the Los Angeles Board of Supervisors into recognizing AIDS as a long term public health problem.

Doctor Roth volunteered to obtain the support of MECLA (Municiple Election Committee of Los Angeles) in this effort.

MOTION: - The Chairman requests DHS staff to prepare a list of all county funds allocated for local AIDS programs throughout California and that Doctor Roth be sent a copy of LA's AIDS funding for his meetings.

6. The need for equipment, secretarial positions and administrative overhead costs for existing and future contractors was expressed by Stan Hadden and from the audience.

Doctor Roth responded that funding has been very limited and that contractors should look to other resources for those needs whenever possible.

7. Doctor Roth suggested that additional federal AIDS funding may be available from Title XX or from the federal Low Income Housing Program (for hospice care).

Doctor Chin commented that Medi-Cal would be appropriate in following this matter and that since Medi-Cal is under DHS, the Director should be appraised by the committee chairman.

ISSUES & RESPONSES

1. The Chairman asked if the planned January 31, 1985 AIDS contractor review meeting could be moved from Orange County to Sacramento so that legislators could attend.

Doctor Chin stated that this may not be appropriate since 1) the meeting may consist of critical review comments, and, 2) it is being held the day after a statewide meeting of local AIDS surveillance personnel so that contractors may attend that meeting. Committee members are welcome to attend either meeting.

2. Doctor Hamilton asked what CDC is doing to interpret data that is collected from AIDS case reports and surveillance activities. Will they be recommending procedures that can be utilized?

Doctor Chin informed the group that CDC has had continuing input into epidemiologic recommendations and is currently developing policy for the follow-up of AIDS in non-risk groups that has shown up lately. He stated that an article will be published on December 15th reporting on a study of 323 individuals who have experienced accidental needle-sticks from AIDS infected blood.

3. Doctor Chin reported on the response received from the DHS Legal Office regarding confidentiality of AIDS patients (attached). Four recommendations were made to develop statutes which will strengthen existing law. Current statutes have been effective as they are written for all infectious diseases, but more may be needed regarding the release of confidential information specific to AIDS.

MOTION: - The Committee recommended that DHS work together with the Legislative Counsel to initiate a confidentiality statute.

Doctor Hamilton expressed concern for the confidentiality of AIDS researchers. This issue has been recently addressed by a group of researchers. Their recommendations are: 1) researchers should not be subpoenaed to give information on their subjects, 2) research records should not be subject to subpoena, 3) regulations should be adopted at the federal, state and local level to ensure the above two points, 4) every AIDS research protocol using human subjects should be reviewed by the human subjects review board, and 5) researchers should avoid using identifiers as much as possible.

4. A question from the audience asked what is being done to remedy discrepancies in the number of AIDS cases being reported by local health departments and the State's statistical reports.

Staff is in the process of comparing all reports, on an individual case basis, to compare and correct any duplications or omissions.

Doctor Roth suggested that the statistics be more specific when showing fatality rates - when the totals are lumped together, the true rate of morbidity over time (100%) is not reflected.

5. Chris Bowman, aide to Senator Marks, raised the issue that Medi-Cal policies are inappropriate in that the disability allowances are too high for AIDS victims to receive benefits.
6. Chris Bowman also asked if there were any rules regarding the absence of Committee members from meetings.

The Chairman concluded that members serve at the pleasure of the appointing power and a motion was adopted whereby Mr. Decker, Doctor Roth and Mr. Hadden will discuss this issue with their respective appointors.

7. The next AIDS Advisory Committee meeting is scheduled for Friday, January 11, 1985 at the State Capitol, Room 2040, from 1:00 to 5:00 P.M.

DECEMBER 10, 1984

7. RESIDENCE	CASES	PERCENT OF TOTAL
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New York	2844	39.1
California	1632	22.4
Florida	508	7.0
New Jersey	443	6.1
Texas	340	4.7
Illinois	155	2.1
Pennsylvania	145	2.0
Massachusetts	121	1.7
District of Columbia	101	1.4
Georgia	92	1.3
Connecticut	85	1.2
Puerto Rico	83	1.1
Maryland	76	1.0
Virginia	67	0.9
Colorado	64	0.9
Washington	61	0.8
Louisiana	60	0.8
Michigan	42	0.6
Ohio	35	0.5
Missouri	31	0.4
Arizona	27	0.4
Indiana	27	0.4
North Carolina	25	0.3
Oregon	21	0.3
Hawaii	20	0.3
South Carolina	19	0.3
Minnesota	17	0.2
Oklahoma	14	0.2
Kentucky	13	0.2
Wisconsin	12	0.2
Rhode Island	11	0.2
Alabama	10	0.1
Nevada	10	0.1
Other States (14)	59	0.8
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Total - USA	7270	100.0

AIDS ACTIVITY, CID, CDC, ATLANTA, GA.

5. Reported Cases of AIDS and Case-Fatality Rates by
by Half-Year Of Diagnosis, 1979 - DECEMBER 10, 1984
California

	NUMBER OF CASES	NUMBER OF DEATHS	CASE-FATALITY RATE
1980 Jan-June	3	3	100%
July-Dec	7	7	100%
1981 Jan-June	16	15	94%
July-Dec	35	25	71%
1982 Jan-June	70	47	67%
July-Dec	130	87	67%
1983 Jan-June	257	152	59%
July-Dec	358	172	48%
1984 Jan-June	439	120	27%
July 1- December 10	315	39	12%
Total*	1632	667	41%

*Table totals include 1 cases diagnosed prior to 1979, and 1 cases with unknown date of diagnosis. Of these 2 cases, 0 are known to have died.

6. AIDS Cases Per Million Population (from the 1980 Census),
by Standard Metropolitan Statistical Area (SMSA) of Residence.
Reported from JUNE 1, 1981 to DECEMBER 10, 1984 - United States

SMSA of Residence	Cases	Percentage of Total	Cases per Million Population
New York, NY	2651	36.5	290.7
San Francisco, CA	851	11.7	261.8
Miami, FL	283	3.9	174.1
Jersey City, NJ	85	1.2	152.6
Newark, NJ	194	2.7	98.7
Elsewhere (irrespective of SMSA)	3206	44.1	15.2
Total - United States	7270	100.0	31.9

AIDS ACTIVITY
CENTER FOR INFECTIOUS DISEASES
CENTERS FOR DISEASE CONTROL
DECEMBER 10, 1984

California Cases Reported to CDC

1. PRIMARY DISEASE*	CASES	PERCENT OF TOTAL	DEATHS	PERCENT DEAD
KS without PCP	556	34.1	147	26.4
PCP without KS	765	46.9	346	45.2
Both KS and PCP	147	9.0	94	63.9
OI without KS or PCP	164	10.0	80	48.8
Total	1632	100.0	667	40.9

*KS = Kaposi's sarcoma
PCP = Pneumocystis carinii pneumonia
OI = Other opportunistic infections

2. AGE	CASES	PERCENT OF TOTAL
Under 5	7	0.4
05 - 13	1	0.1
13 - 19	5	0.3
20 - 29	291	17.8
30 - 39	796	48.8
40 - 49	391	24.0
Over 49	141	8.6
Unknown	0	0.0
Total	1632	100.0

3. RACE/ETHNICITY	CASES	PERCENT OF TOTAL
White, not Hispanic	1329	81.4
Black, not Hispanic	131	8.0
Hispanic	122	7.5
Other	9	0.6
Unknown	41	2.5
Total	1632	100.0

4. Patient Characteristics**	MALES		FEMALES		TOTAL	
	CASES	PERCENT OF MALES	CASES	PERCENT OF FEMALES	CASES	PERCENT OF TOTAL
Homosexual or Bisexual	1549	96.0	0	0.0	1549	94.9
Intravenous (IV) Drug User	22	1.4	4	21.1	26	1.6
Haitian	2	0.1	0	0.0	2	0.1
Hemophiliac	6	0.4	0	0.0	6	0.4
Heterosexual Contact	2	0.1	1	5.3	3	0.2
Transfusion	10	0.6	5	26.3	15	0.9
Parent at Risk	0	0.0	2	10.5	2	0.1
None Apparent/Unknown	23	1.4	7	36.8	29	1.8
Total	1613	100.0	19	100.0	1632	100.0

**Patient characteristics are ordered hierarchically: cases with multiple characteristics are tabulated only in the group listed first.

Memorandum

To : D.L. Gunter, Chief
VD Control Program

Date : December 12, 1984

Subject: Outline of Topics
discussed during
Epidemiology/
Surveillance Meeting.

From : Augie Detres, SCDR



The AIDS epidemiology/Surveillance Group held their second workshop in San Francisco on November 5, 1984. Twenty-two participants representing thirteen counties and the State AIDS Program were present at the meeting.

Four major topics were discussed:

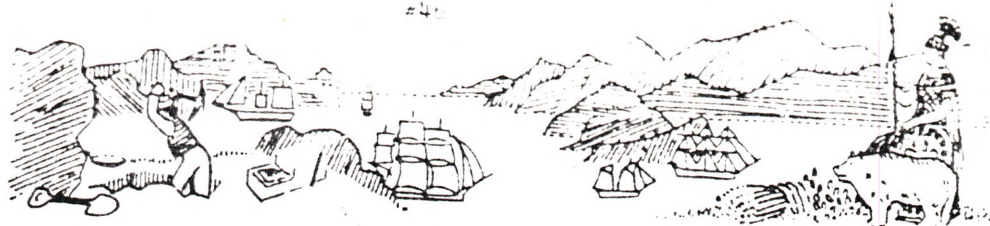
1. Active and passive surveillance methods
2. AIDS reporting problems
3. Methods of transferring statistical data to counties
4. The use of other medical record systems such as death certificates, tumor registries, and State Disability Claims offices as supplemental sources to validate the local surveillance systems and to evaluate the completeness of routine reporting.

AD:so

California Morbidity

Weekly Report from the

Infectious Disease Section
State Department of Health Services



LABORATORY TESTING FOR THE AIDS VIRUS

An increasing amount of data have been developed in the past year to indicate that a human retrovirus variously named the lymphadenopathy virus (LAV), the human T-cell lymphotropic virus, type III (HTLV-III) and the AIDS-related virus (ARV) represents the etiologic agent of AIDS. Hereafter, these candidate viruses will be referred to as the "AIDS virus".

However, several major questions related to the development of AIDS remain unanswered. The primary questions are 1) whether other factors (i.e., environmental or host co-factors, or other infectious agents) may be needed, in addition to infection with the AIDS virus, for the development of irreversible and ultimately fatal AIDS, and 2) what is the precise clinical spectrum of infection due to this "etiologic" virus. Regarding this latter question, there is an urgent need to determine what proportion of exposed persons will develop asymptomatic infection with subsequent specific immunity to the AIDS virus; what proportion will develop only lymphadenopathy syndrome; and what proportion will develop irreversible and ultimately fatal AIDS. For each of these groups, there is also a pressing need to determine how many remain infectious after acute infection (carriers) and for how long. It will be very important to determine whether such infectiousness ends after specific intervals or whether it may persist indefinitely, either intermittently or continuously.

Tests to measure antibodies to the AIDS virus have been described and others are being developed. Such tests are presently available on an investigational basis and they are expected to be licensed in early 1985. The California AIDS Task Force and other groups such as the Conference of State and Territorial Public Health Laboratory Directors, and the California Conference of Local Health Officers (CCLHO) are very concerned that these tests may be released prematurely

for general use, i.e., before the diagnostic and prognostic significance of positive or negative test results, especially in asymptomatic persons, can be determined. Given the very large number of persons who might be screened (tested), some may be incorrectly classified as having been infected with the AIDS virus, even when the test is technically perfected and even if such tests have a relatively low false-positivity rate.

A positive test finding in asymptomatic persons will likely engender considerable personal alarm which may not be avoidable. The majority of persons (in high risk groups for AIDS) who have AIDS related complex (ARC) will show positive results to these tests, even though it is likely that most of them will not go on to develop the full manifestations of irreversible and ultimately fatal AIDS. Such results may, in some circumstances, require appropriate medical follow-up and possible public health action. However, it is essential that the confidentiality of these results (other than restricted access for necessary public health purposes) be protected as much as possible. These tests are now being used in research centers to study AIDS and ARC patients. In addition to their use in the evaluation of patients suspected to have AIDS, one of the first routine uses of the AIDS virus antibody tests will likely be to screen donated blood, just as all blood is currently screened for hepatitis B surface antigen to prevent transfusion-transmitted hepatitis B. Guidelines for the medical and public health response to positive test results are in the process of development at national and state levels, and should be available before licensure of these tests. Such initial guidelines will require modification as experience and more data become available regarding the clinical and public health significance of these laboratory tests.

Table 1. Reported Cases of Selected Notifiable Diseases in California, 46th Week Ending November 17, 1984

Disease	Cases Reported This Week			Total Cases Reported to Date		
	1984	1983	1982	1984	1983	1982
Coccidioidomycosis	4	3	6	370	270	340
Encephalitis, Viral	2	2	5	148	143	157
Food Poisoning (excludes Botulism)	25	-	-	556	669	232
Gonorrhea	2,939	1,375	2,473	86,469	94,706	98,867
Hepatitis Type A (Infectious)	139	115	114	6,150	4,122	3,737
Hepatitis Type B (Serum)	108	91	101	4,620	3,864	3,317
Hepatitis Non A - Non B	21	23	31	1,015	981	732
Hepatitis Type Unspecified	31	19	44	1,095	1,166	1,418
Malaria	6	5	5	325	246	340
Measles	-	-	1	317	173	818
Meningitis, Viral	35	35	38	1,053	1,217	1,217
Meningococcal Infections	1	4	6	204	195	267
Mumps	5	14	10	367	328	453
Pertussis	4	8	2	143	104	111
Rabies, Animal	10	7	4	502	378	469
Rubella (German Measles)	2	2	4	178	269	1,382
Salmonellosis	71	88	106	3,439	3,894	2,930
Shigellosis	139	71	112	4,429	4,429	3,756
Streptococcal Infections, Respiratory	561	359	456	20,300	19,919	21,270
Syphilis, Total	253	114	211	8,359	9,984	9,053
Primary and Secondary	84	36	98	3,492	4,378	3,740
Tuberculosis (Total Reports)	32	53	66	2,863	3,159	3,230
Typhoid Fever	7	-	-	-	-	-

1/81 - 10/31/84

*Berkeley City: 6 cases

San Francisco
County: 690 cases

TOTAL AS OF 10/31/84: 1.558 reported to
California AIDS Project.

(An additional 41 cases have been diagnosed out-of-state, but now reside in California.)

AIDS CASES BY COUNTY
OF RESIDENCE AT ONSET OF ILLNESS

January 1981 - October 31, 1984

<u>CODE</u>	<u>COUNTY</u>	<u>CALIFORNIA TOTAL</u>
90	San Francisco	690
70	Los Angeles	551
30	Orange	59
60	Alameda (ex. Berkeley)	52
80	San Diego	45
43	Santa Clara	21
21	Marin	18
07	Contra Costa	17
49	Sonoma	17
41	San Mateo	16
33	Riverside	15
34	Sacramento	10
36	San Bernardino	9
65	Berkeley	6
27	Monterey	5
10	Fresno	4
15	Kern	3
23	Mendocino	3
40	San Luis Obispo	3
17	Lake	2
42	Santa Barbara	2
50	Stanislaus	2
56	Ventura	2
09	El Dorado	1
13	Imperial	1
24	Merced	1
39	San Joaquin	1
48	Solano	1
53	Trinity	1
03	Amador	0
45	Shasta	0
SUBTOTAL		1,558
(Out-of-State)		+ 41
GRAND TOTAL		<u>1,599</u>

Infectious Disease Section

J. Chin, M.D., Chief

State Virology Laboratory

R. Emmons, M.D., Chief

AIDS Advisory Committee

(9) Members

CA Task Force on AIDS

18 Members

VD Control Program

D.L. Gunter, Chief

T. Ault, Asst. Chief

Medical Consultant

(Vacant) PHMO III

AIDS Project

J. Felten, Project Mgr.
HPM (Acting)

(Vacant) Asst. Mgr.

(Vacant) Office Asst.

Field Services

R. Fox, PHA

Surveillance/Epidemiology

A. Detres, Sup. CDR

G. Crawford, No. Bay Area
(Vacant) So. Bay Area

M. Bursaw, San Diego Area
G. Wertzberger, Orange Area
(Vacant) Central Valley

Statistics

K. Brock, MSW

J. Shepard

Information/Education

L. Kamel, PHD

December 14, 1984

Concerns of California Blood Banks

Representatives of California blood banks which provide more than 70% of the blood used within the state have convened during the past month to review specific issues and concerns on the subject of testing blood for the antibody to the HTLV-III retrovirus, the presumed viral agent of the Acquired Immune Deficiency Syndrome (AIDS), and the risk of transfusion associated AIDS.

When a test for anti-HTLV-III is available, now estimated to be no earlier than April of 1985, it appears that all licensed California blood collection agencies will use the test to screen donors and will take measures to preclude the transfusion of donations which contain the antibody. It is recognized, however, that this test will not be 100% sensitive and a very small percentage of donations may test "false negative" and be transfused. Therefore, the absolute elimination of AIDS resulting from transfusion cannot be guaranteed.

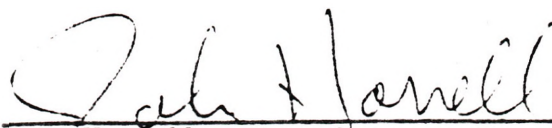
In addition, the possibility exists that such a test for antibody to HTLV-III may not meet federal requirements to be mandated so that donors might have to provide informed consent before being tested. Further, blood imported for transfusion from outside the state may not have been screened for this antibody.

A third major concern is the current "perceived" public concern over the disclosure of donor identity in situations where AIDS is linked to a blood transfusion; this may apply to donors found to have anti-HTLV-III. There is one case in Northern California where efforts are now being made to discover the identity of the donors involved in a transfusion associated AIDS case for the presumed reason of taking direct action against the donor(s). Recent publicity about a new law in Australia which makes the donation of blood by a high risk donor for AIDS

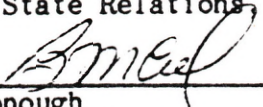
a punishable offense has only increased the anxiety of people who fear potential retaliation by the courts.

To help increase the safety of blood transfusion within the state of California, the blood bank representative proposed the following action:

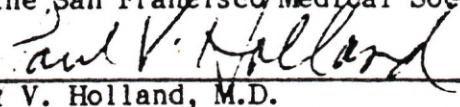
1. Require, through regulatory authority, that all blood and blood products transfused within the State be tested for evidence of exposure to the probable causative agent of AIDS, e.g., perform an anti-HTLV-III test on all donor bloods.
2. Change the State Hepatitis Donor Deferral Registry to a "Permanent Deferral Registry" and include the names of individuals who are "permanently deferred from blood donations" without identifying the reason for deferral. Thus, for example, individuals found to be specifically positive for anti-HTLV-III, a history of viral hepatitis, or a diagnosis of AIDS, would be on the Registry, but none of these reasons would be identifiable as such.
3. Enact legislation that would protect donor identification from the process of discovery and, further, provide that the disclosure of donor information by any individual or agency be made a punishable offense if not done under law or with the donor's consent.



John Horrell
Director, State Relations, American Red Cross



Brian McDonough
Chief Executive Officer, Irwin Memorial Blood Bank
of the San Francisco Medical Society



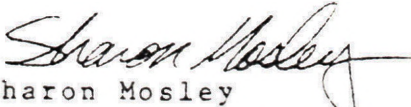
Paul V. Holland, M.D.
Medical Director/CEO of the
Sacramento Medical Foundation Blood Center

Memorandum

To : James Chin, M.D., Chief
Infectious Disease Section
2151 Berkeley Way, Room 708
Berkeley, CA 94704

Date : December 11, 1984

Subject: Confidentiality of AIDS
Research Data

From :  Sharon Mosley
Office of Legal Services
714 P Street, Room 1216
Sacramento, CA 95814
8/492-1186

You requested a summary of current legal protections of the confidentiality of AIDS patient data which is obtained by the Infectious Disease Section of the Department of Health Services (DHS). Below is a summary of current provisions of California law and a brief analysis of how these provisions interrelate.

California Constitution, Article I, Section I

The California Constitution (unlike most other state constitutions and the United States Constitution) specifically guarantees the right to privacy. Calif. Const. Art. I, §1. This right is not absolute and may be outweighed by compelling public health concerns.

Health and Safety Code Section 211.5

"All records of interviews, written reports and statements procured by the state department or by any other person, agency or organization acting jointly with the state department, in connection with special morbidity and mortality studies shall be confidential insofar as the identity of the individual patient is concerned and shall be used solely for the purposes of the study. The furnishing of such information to the state department or its authorized representative, or to any other co-operating individual, agency or organization in any such special study, shall not subject any person, hospital, sanitarium, rest home, nursing home, or other organization furnishing such information to any action for damages. The provisions of this section shall not apply to general morbidity and mortality studies customarily and continuously conducted by the state department and which do not involve patient identification.

Nothing in this section shall prohibit the publishing by the state department of statistical compilations relating to morbidity and mortality studies which do not identify individual cases and sources of information or religious affiliations."

This section restricts the release of patient-identifying information and limits the use of such data to the purposes of the investigations of morbidity and mortality. This section has been interpreted to supersede the conditions of disclosure of the Information Practices Act (discussed below) and to permit exchange of confidential data only among individuals, agencies, or organizations co-operating with DHS in connection with the morbidity and mortality studies. Release of such data to any person, organization or other government agency for any purposes not connected with such studies would be prohibited.

X If patient-identifying information is subpoenaed, it has been the practice of DHS to obtain an agreement with the subpoenaing party that all patient-identifying information will be deleted. If such an agreement cannot be reached, DHS may seek a protective order from the court to keep this information confidential (Code of Civil Procedure, Section 1987.1). An order from the court might require production but limit the use and disclosure of records, require production with the names deleted, provide sanctions for misuse of records or set forth other methods for assuring confidentiality.

Information Practice Act of 1977 (Act) (Civil Code Section 1798 et seq.)

The general purpose of the Information Practices Act is to control the collection and dissemination of personal data and to allow individuals access to personal data about themselves. "Personal information" as defined in the Act includes information about an individual's medical history. The disclosure of "personal information" is prohibited unless specific conditions which are listed in Civil Code Section 1798.24 are applicable. However, pursuant to general rules of statutory construction, if any conflict exists between the provisions of the Act and Health and Safety Code Section 211.5, the provisions of the latter would be controlling. Because 211.5 specifically addresses a particular subject (confidentiality of special morbidity and mortality study records, its provisions supersede a statute which generally covers a subject (maintenance and release of personal data). Following this line of reasoning, if 211.5 is interpreted to prohibit release of data in a situation listed in Civil Code §1798.24, the data could not be released. Section 1798.72 of the Act provides as follows:

"Nothing in this chapter shall be construed to authorize the disclosure of any record containing

personal information, other than to the subject of such records, in violation of any other law."

Public Records Act (Government Code Section 6250 et seq.)

The Public Records Act requires disclosure of records of a state agency unless the records are exempt from disclosure pursuant to section 6254 or section 6255. Records containing confidential AIDS patient data would be exempt from disclosure under both subdivision (c) ("personnel, medical or similar files, the disclosure of which would constitute an unwarranted invasion of personal privacy") and subdivision (k) ("records the disclosure of which is exempted or prohibited pursuant to provisions of federal or state law ...")

You also requested a review of federal law and regulations concerning confidentiality which would be applicable to federally-funded AIDS research. We have identified the following requirements which may be applicable.

Privacy Act (5 USC 552a, 45 CFR Part 5b, 41 CFR Chapter 3, Sections 3-1.327 and 3-1.327.4)

The Privacy Act and implementing regulations may be applicable to contractors with the Department of Health and Human Services (or other federal agencies) when the contractor is required to maintain or operate a system of records to accomplish a departmental function. The Privacy Act permits disclosure of personal data by a federal agency or contractor without consent of the subject individual under circumstances listed in 5 USC 552a(b) and 45 CFR §5b.9(b).

Protection of Human Subjects (42 USC 2891-3(a), 45 CFR Part 46)

The provisions of this part are applicable to all research involving human subjects conducted by HHS or funded in whole or in part by a Department grant, contract, cooperative agreement or fellowship.

45 CFR §46.11(a)(7) requires that the Institutional Review Board approve a research project only if there are "adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data". Additionally, 46.116(a)(5) requires that an informed consent document include "a statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained".

Public Health Service Act, 42 USC 242a(a) (Research on mental health and alcohol and drug abuse)

Some federally funded AIDS research projects have received a Certificate of Confidentiality which assures that the identity of

all subjects of research may be withheld from all persons not connected with the research. This protection assures that researchers "may not be compelled in any Federal, State, or local civil, criminal, administrative, legislative, or other proceedings to identify such individuals". 42 USC 424a.

The authority to provide this type of protection of subject identity is applicable to research on mental health, including research on the use and effect of alcohol and other psychoactive drugs. Therefore, the applicability of this protection to AIDS research is limited. Apparently those projects receiving the Certificate of Confidentiality are federally-funded projects which have included research questions related to mental health and to drug and alcohol abuse.

Finally, you have requested that we identify areas where current legal protections could be strengthened to best protect the confidentiality of AIDS research subjects. You have also asked how patient-identifying information reported to the Infectious Disease Section on AIDS cases can best be protected. We have listed several areas where more specific statutory requirements may be desirable.

- ✓ 1. A statute which specifically controls the confidentiality of data related to AIDS research subjects could more clearly define when such data may or may not be disclosed.
- ✓ 2. A statute could create a mandatory requirement that DHS seek and that the court issue a protective order when patient-identifying information is sought pursuant to a subpoena.
- ✓ 3. A statute could more specifically limit the release of information obtained by the Infectious Disease Section regarding AIDS as a reportable disease. In limiting the access to and use of this data such a statute should take into account what other public health interests may require protection (i.e., the availability of such data to blood banks).
- ✓ 4. If the State sought to provide Certificates of Confidentiality related to state-funded AIDS research, statutory authority would be necessary. We recommend that legislation to create such authority address the relationship of such protections to the need to require reporting of AIDS cases to the Infectious Disease Section.

If we can be of further assistance, please do not hesitate to call.

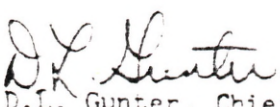
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Memorandum

To : Area Supervisors

Date : December 11, 1984

Subject: AIDS Update; Supplemental AIDS Prevention Messages to be Incorporated into STD Interviewing and Counseling of ALL STD Patients

From : 
D.L. Gunter, Chief
VD Control Program

Since the beginning of 1983, Acquired Immune Deficiency Syndrome (AIDS) morbidity and mortality has increased, particularly in California, at an alarming rate. A total of 1,712 cases (692 deaths) have been reported to the California Department of Health Services as of November 30, 1984, and 7,136 cases (1391 deaths) have been reported to CDC. Thus, cases are doubling every nine months.

The HTLV III virus has been identified as the probable causative agent of AIDS. The development of a cure or a vaccine for AIDS does not seem promising at this time. Therefore, AIDS surveillance, epidemiology, and information and education continues to be of vital importance in the study and prevention of the syndrome.

Centers for Disease Control has long recognized the possibility of AIDS entering this heterosexual population in this country. In Zaire, Africa, AIDS epidemiology clearly indicates this syndrome occurring in the heterosexual population. In San Francisco, twelve heterosexual cases have been reported.

Although bi/homosexually active males remain, by far, the highest group at risk of contracting AIDS, there is a need to reach the heterosexual population with AIDS information and education. Please incorporate the following AIDS risk-reduction strategies into the overall STD prevention plan and individual lifestyles of all STD patients.

A listing of alcohol and drug abuse centers should be established and available to patients, since abstaining or lowering alcohol/drug use may further help minimize high-risk sexual activity, and sustain better health to resist infections.

Your assistance in reaching individuals with this information may save lives! AIDS pamphlets, brochures, videos, and other materials are available at the California AIDS Project on request. Please call G.W. Levi Kamel, Ph.D., AIDS Educational Services Coordinator, for questions and comments at (916) 323-1450 or ATSS 473-1450.

Attachment:

DLG:so

AIDS Prevention Tips

1. Reduce the number of different partners . The more partners with whom one contacts sexually, the greater the statistical probability of contracting disease, especially among homosexually active males, intravenous drug abusers, and male and female prostitutes.
2. Know your partner . Do not have sexual contact with persons who continue to have compulsive or unsafe sex with large numbers of persons.
3. Use alternative forms of intimacy that do not involve the exchange of body fluids (e.g. semen, urine, blood, fecal matter). Various community projects assist high-risk individuals with alternative intimacy.
4. Use condoms . When used with water soluble lubricants, condoms may offer some protection against AIDS and other STDs. Learn the advantages and proper use of condoms.
5. Keep the names and addresses of your sexual partners.
6. Relay these risk-reduction messages to friends .
7. Learn more about AIDS , including early signs and symptoms, as well as healthier alternatives for sexual expression.



LABORATORY TESTING FOR THE AIDS VIRUS

An increasing amount of data have been developed in the past year to indicate that a human retrovirus variously named the lymphadenopathy virus (LAV), the human T-cell lymphotropic virus, type III (HTLV-III) and the AIDS-related virus (ARV) represents the etiologic agent of AIDS. Hereafter, these candidate viruses will be referred to as the "AIDS virus".

However, several major questions related to the development of AIDS remain unanswered. The primary questions are 1) whether other factors (i.e., environmental or host co-factors, or other infectious agents) may be needed, in addition to infection with the AIDS virus, for the development of irreversible and ultimately fatal AIDS, and 2) what is the precise clinical spectrum of infection due to this "etiologic" virus. Regarding this latter question, there is an urgent need to determine what proportion of exposed persons will develop asymptomatic infection with subsequent specific immunity to the AIDS virus; what proportion will develop only lymphadenopathy syndrome; and what proportion will develop irreversible and ultimately fatal AIDS. For each of these groups, there is also a pressing need to determine how many remain infectious after acute infection (carriers) and for how long. It will be very important to determine whether such infectiousness ends after specific intervals or whether it may persist indefinitely, either intermittently or continuously.

Tests to measure antibodies to the AIDS virus have been described and others are being developed. Such tests are presently available on an investigational basis and they are expected to be licensed in early 1985. The California AIDS Task Force and other groups such as the Conference of State and Territorial Public Health Laboratory Directors, and the California Conference of Local Health Officers (COLHO) are very concerned that these tests may be released prematurely

for general use, i.e., before the diagnostic and prognostic significance of positive or negative test results, especially in asymptomatic persons, can be determined. Given the very large number of persons who might be screened (tested), some may be incorrectly classified as having been infected with the AIDS virus, even when the test is technically perfected and even if such tests have a relatively low false-positivity rate.

A positive test finding in asymptomatic persons will likely engender considerable personal alarm which may not be avoidable. The majority of persons (in high risk groups for AIDS) who have AIDS related complex (ARC) will show positive results to these tests, even though it is likely that most of them will not go on to develop the full manifestations of irreversible and ultimately fatal AIDS. Such results may, in some circumstances, require appropriate medical follow-up and possible public health action. However, it is essential that the confidentiality of these results (other than restricted access for necessary public health purposes) be protected as much as possible. These tests are now being used in research centers to study AIDS and ARC-patients. In addition to their use in the evaluation of patients suspected to have AIDS, one of the first routine uses of the AIDS virus antibody tests will likely be to screen donated blood, just as all blood is currently screened for hepatitis B surface antigen to prevent transfusion-transmitted hepatitis B. Guidelines for the medical and public health response to positive test results are in the process of development at national and state levels, and should be available before licensure of these tests. Such initial guidelines will require modification as experience and more data become available regarding the clinical and public health significance of these laboratory tests.

Table 1. Reported Cases of Selected Notifiable Diseases in California, 46th Week Ending November 17, 1982

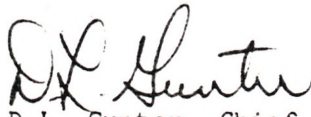
Disease	Cases Reported This Week			Total Cases Reported to Date		
	1984	1983	1982	1984	1983	1982
Coccidioidomycosis	4	3	6	370	270	340
Encephalitis, Viral	2	2	5	148	143	157
Food Poisoning (excludes Botulism)	25	-	-	556	669	232
Gonorrhea	2,939	1,375	2,473	86,469	94,706	98,867
Hepatitis Type A (Infectious)	139	115	114	6,150	4,122	3,737
Hepatitis Type B (Serum)	108	91	101	4,620	3,864	3,317
Hepatitis Non A - Non B	21	23	31	1,015	981	732
Hepatitis Type Unspecified	31	19	44	1,095	1,166	1,418
Malaria	6	5	5	325	246	340
Measles	-	-	1	317	173	818
Meningitis, Viral	35	35	38	1,053	1,217	1,217
Meningococcal Infections	1	4	6	204	195	267
Mumps	5	14	10	367	326	453
Pertussis	4	6	2	143	104	111
Rabies, Animal	10	7	4	502	378	460
Rubella (German Measles)	2	2	4	178	260	1,312
Salmonellosis	71	88	106	3,439	3,894	1,831
Shigellosis	139	71	112	4,420	4,420	3,751
Streptococcal Infections, Respiratory	501	359	456	20,300	19,910	21,270
Syphilis, Total	253	114	211	8,359	9,984	10,053
Primary and Secondary	84	36	98	3,492	4,378	3,741
Tuberculosis (Total Reports)	32	53	66	2,803	3,154	3,230
Typhoid Fever	-	-	-	-	-	-

Memorandum

To : AIDS Advisory Committee Members

Date : December 21, 1984

Subject: AIDS Meeting
Minutes


From : D.L. Gunter, Chief
VD Control Program

Enclosed are the minutes of the December 14, 1984 AIDS Advisory Committee meeting. Attachments that were distributed to the members at the meeting have been included here only for those not in attendance.

The next Committee meeting is scheduled for January 11, 1985 from 1:00 A.M. to 5:00 P.M. in room 2040 of the State Capitol in Sacramento.

Attachments

JF:so

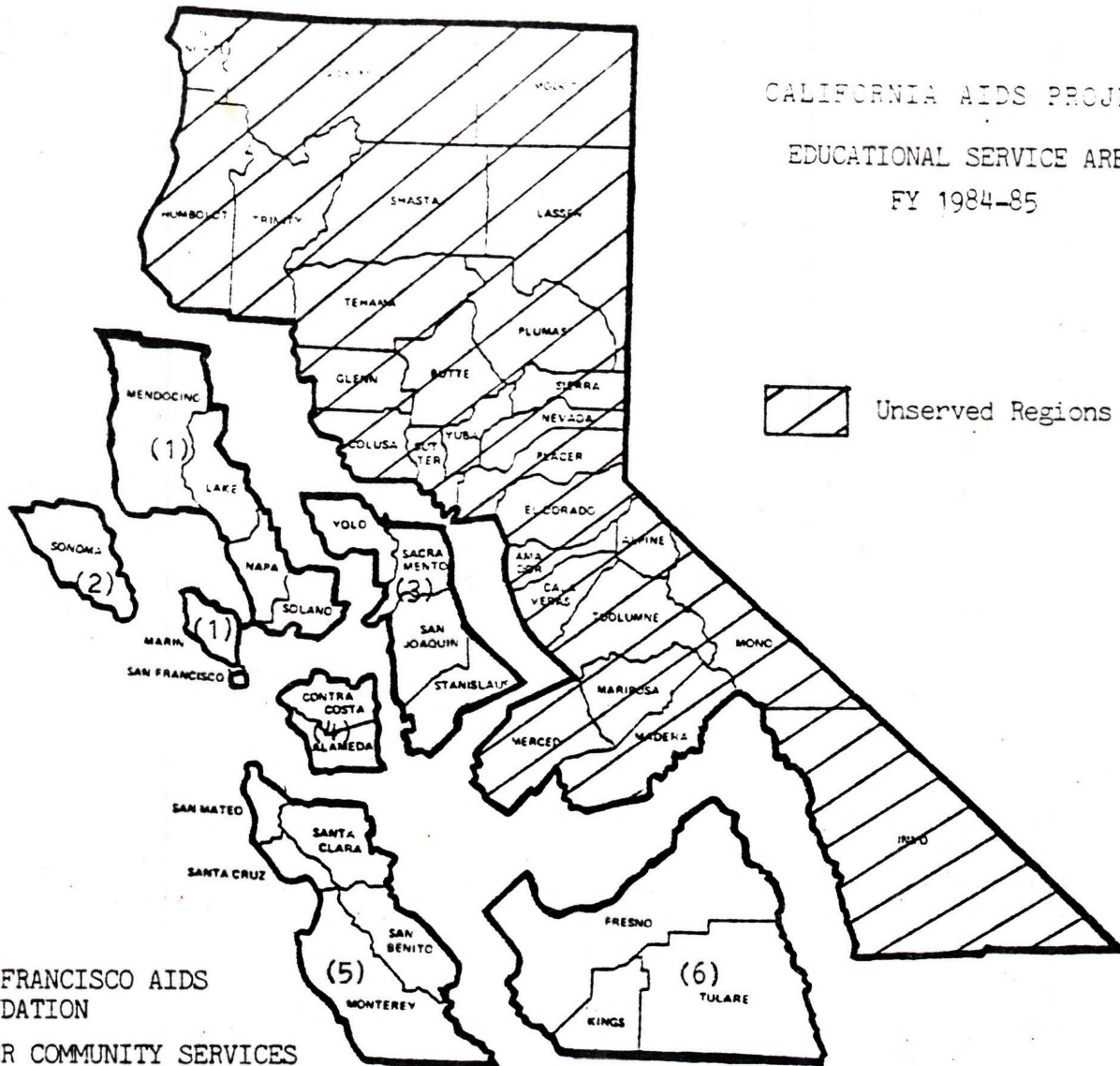
CALIFORNIA AIDS PROJECT
EDUCATIONAL SERVICE PROJECT---FISCAL YEAR 1984-85

PROJECT	CONTRACTOR	COORDINATOR	SERVICE AREA	SERVICE CATEGORIES	AMT.
1) AIDS VIDEO LIBRARY	Multicultural Lesbian and Gay Studies Program, U.C. Berkeley	Lisa Raffel (415) 642-6942	All counties	1. Prevention 2. Provider Training 3. Public Education	1K
2) CALIFORNIA AIDS HOT LINE SYSTEM	AIDS Project/L.A.; San Francisco AIDS Foundation	Dan Schoonover (213) 871-1284 Lyn Paleo (415) 864-4376	Northern California 800-FOR-AIDS Southern California 800-922-AIDS	1. Prevention 2. Provider Training 3. Public Education	28K
3) CALIFORNIA AIDS PROJECT	California Department of Health Services	Tom Ault (916) 322-2087	Statewide Coordinating Unit	1. Prevention 2. Provider Training 3. Public Education	2K
4) CENTRAL VALLEY OUTREACH	Gay United Services	Kay Vanderford (209) 264-2436	Fresno, Tulare, King counties	1. Prevention 2. Provider Training 3. Sig. Others	20K
5) COMMUNITY BUSINESS PROJECT	San Francisco AIDS Foundation	Lyn Paleo (415) 864-4376	San Francisco	1. Prevention	31K
6) COMMUNITY EDUCATION	San Diego AIDS Project	Hal Frank, Ph.D. (619) 294-2437	San Diego County	1. Prevention 2. Provider Training 3. Public Education	40K
7) COMMUNITY EDUCATION	San Diego Health Dept.	J. Friedenbergl (619) 236-2705	San Diego County	1. Prevention 2. Provider Training 3. Public Education	21K
8) COMPUTERIZED AIDS INFORMATION NETWORK (CAIN)	GLCSC, Los Angeles; San Francisco AIDS Foundation	Bob Hilliard (415) 864-4376 Russ Toth (213) 464-7400	All counties	1. Prevention 2. Provider Training 3. Public Education	64K
9) DESERT AIDS PROJECT	Community Counseling and Consultation, Inc.	George Sonsel, LSW (619) 323-2118	Riverside, San Bernardino counties	1. Prevention 2. Provider Training	25K

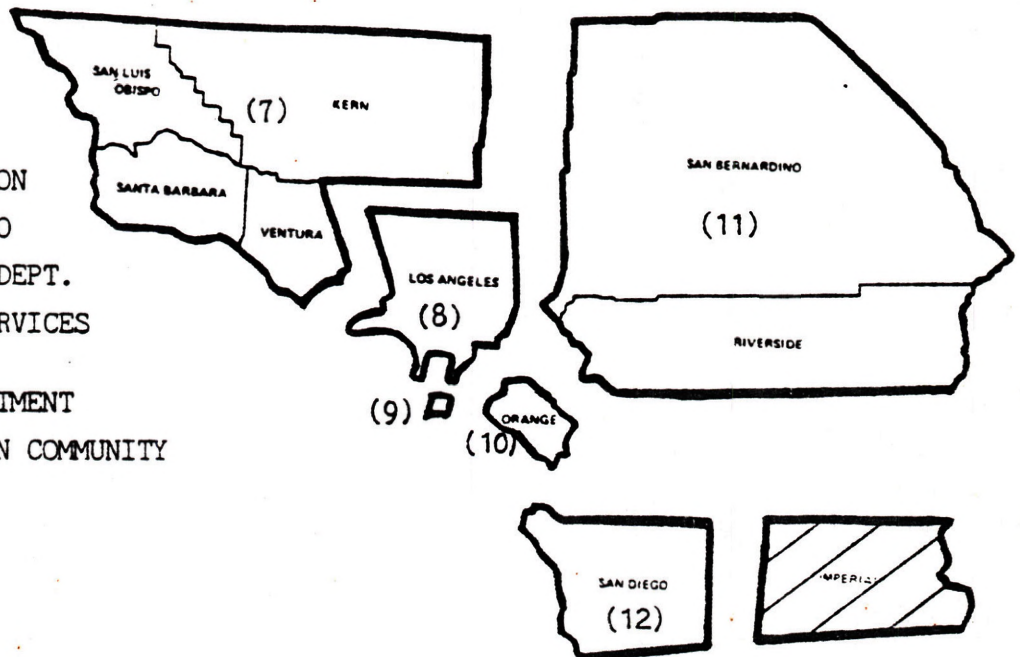
PROJECT	CONTRACTOR	COORDINATOR	SERVICE AREA	SERVICE CATEGORIES	AMT.
10) EAST BAY AIDS EDUCATION PROJECT	Pacific Center for Human Growth	Jeremy Landau (415) 548-8283	Alameda, Contra Costa counties	1. Prevention 2. Provider Training 3. Sig. Others	54K
11) HEMOPHILIA EDUCATION	Orthopaedic Hospital	Gary Bruno, LCSW (213) 742-1358	Los Angeles County	1. Patient Information 2. Sig. Others 3. Provider Training	22K
12) IV USER OUTREACH	Youth Projects, Inc.	J. Newmeyer, Ph.D (415) 431-2450	San Francisco County	1. Prevention	10K
13) L.A. CARES	GLCSC, Los Angeles; AIDS Project/L.A.	Hugh Rice, MPH (213) 464-7400 B. Misenhimer (213) 871-1284	Los Angeles County	1. Prevention	170K
14) L.A. HEALTH EDUCATION	AIDS Project/L.A.	Judy Spiegel, MPH (213) 871-1284	Los Angeles County	1. Provider Training	42K
15) LONG BEACH COMMUNITY	Long Beach City Health Department	Ray Kincade, RN (213) 427-7421	Los Angeles (Long Beach only)	1. Prevention 2. Provider Training 3. Public Education	21K
16) NORTH VALLEY AIDS EDUCATION PROJECT	Sacramento AIDS Foundation	Art McDermott, MA (916) 448-2437	Yolo, Sacramento, San Joaquin, Stanislaus counties	1. Prevention 2. Provider Training 3. Sig. Others	20K
17) NORTHERN CALIFORNIA OUTREACH	San Francisco AIDS Foundation	Lyn Paleo (415) 864-4376	Alameda, Contra Costa, Lake, Marin, Mendocino, Napa, Solano, Sonoma	1. Prevention 2. Provider Training 3. Public Education	21K
18) QUAD-COUNTIES	Santa Barbara Health Department	Jerry White, MA (805) 967-2311	Santa Barbara, San Luis Obispo, Ventura, Kern counties	1. Prevention 2. Provider Training 3. Public Education	29K

PROJECT	CONTRACTOR	COORDINATOR	SERVICE AREA	SERVICE CATEGORIES	AMT.
19) SAN FRANCISCO AIDS EDUCATION	San Francisco AIDS Foundation	Jackson Peyton (415) 864-4376	San Francisco County	1. Prevention 2. Provider Training 3. Public Education	35K
20) SONOMA AIDS EDUCATION	River Community Services	Jim Stoll (707) 887-2226	Sonoma County	1. Prevention 2. Provider Training 3. Public Education	22K
21) SOUTH BAY EDUCATION	Santa Clara County Health Department and AIDS Foundation	B. DeArmond, M.D. (408) 299-5858	Santa Cruz, Santa Clara, San Mateo, San Benito, Monterey	1. Prevention 2. Provider Training	53K
22) THE AIDS RESPONSE PROGRAM	Orange County Gay and Lesbian Community Services Center	Randy Pesquiera (714) 534-0862	Orange, San Bernardino, Riverside counties	1. Prevention 2. Provider Training	50K
23) WOMEN AND AIDS	San Francisco AIDS Foundation	Lyn Paleo (415) 864-4376	San Francisco County	1. Prevention	9K

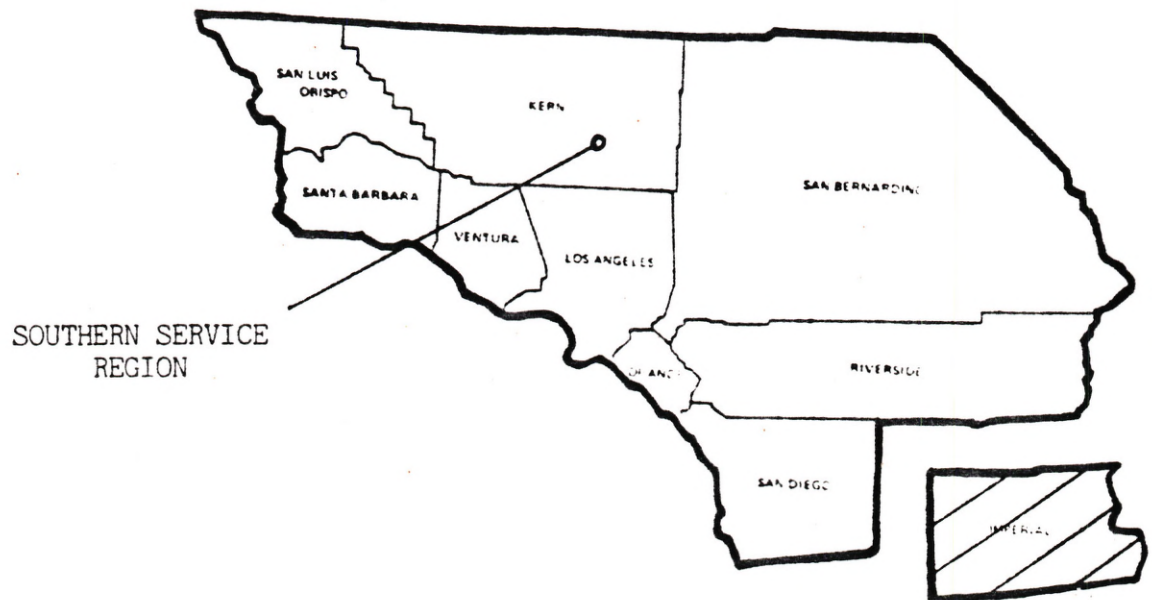
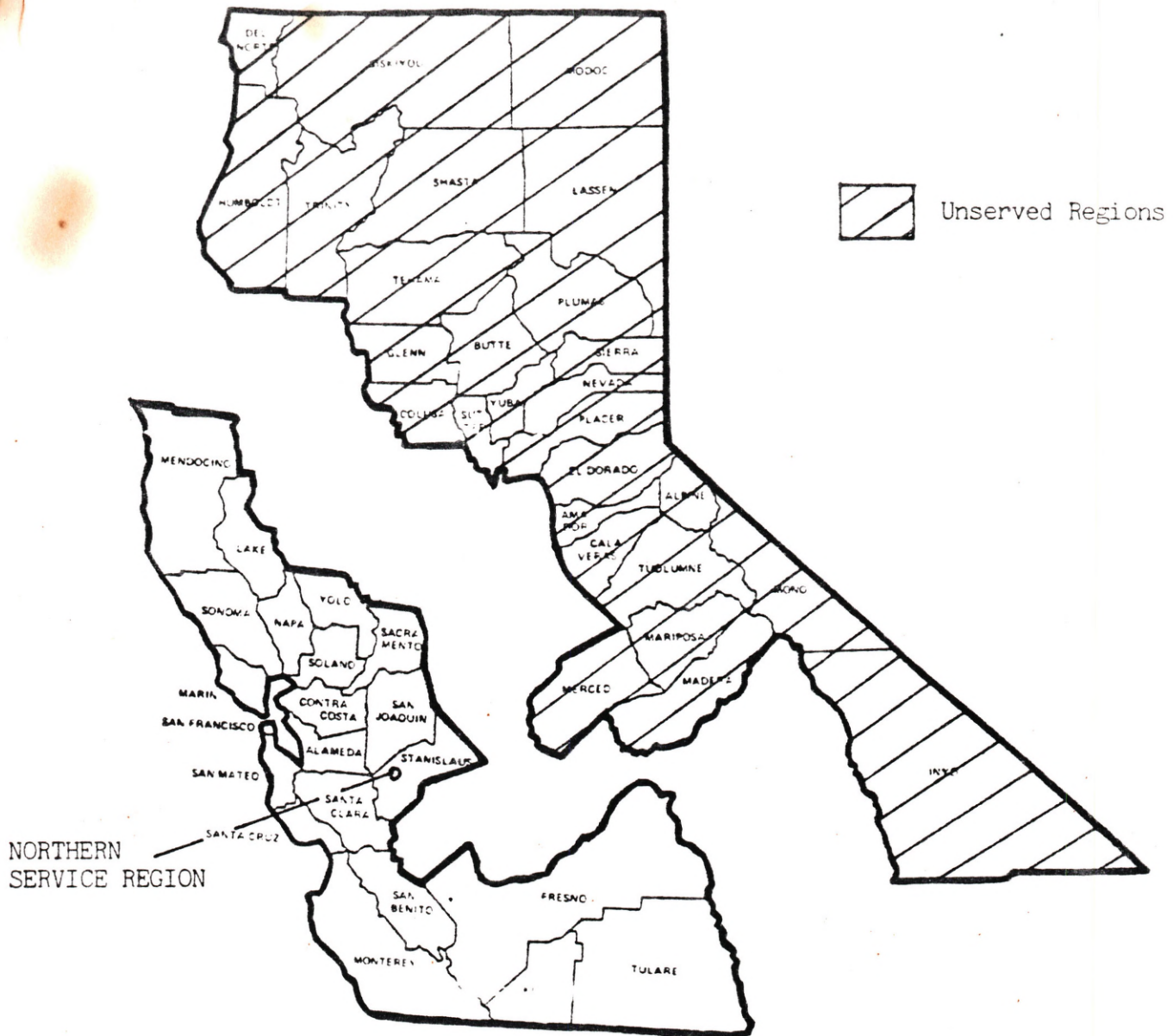
CALIFORNIA AIDS PROJECT
EDUCATIONAL SERVICE AREAS
FY 1984-85



- (1) SAN FRANCISCO AIDS FOUNDATION
- (2) RIVER COMMUNITY SERVICES
- (3) SACRAMENTO AIDS FOUNDATION
- (4) PACIFIC CENTER FOR HUMAN GROWTH
- (5) SANTA CLARA COUNTY HEALTH DEPARTMENT AND AIDS FOUNDATION
- (6) GAY UNITED SERVICES OF FRESNO
- (7) SANTA BARBARA COUNTY HEALTH DEPT.
- (8) GAY AND LESBIAN COMMUNITY SERVICES CENTER (GLCSC), LOS ANGELES
- (9) LONG BEACH CITY HEALTH DEPARTMENT
- (10) ORANGE COUNTY GAY AND LESBIAN COMMUNITY SERVICES CENTER (OCGLCSC)
- (11) DESERT AIDS PROJECT
- (12) SAN DIEGO AIDS PROJECT



CALIFORNIA AIDS PROJECT
EDUCATIONAL SERVICES REGIONS
FY 1984-85



CALIFORNIA AIDS PROJECT
FACT SHEET

STATEWIDE LITERATURE DISTRIBUTION SYSTEM

Of the 16 AIDS education contractors funded for FY 1984-85, 12 of them have developed or are developing a network to distribute printed literature. Outlets for materials include social service agencies, churches, gay community social and recreational clubs, night clubs, restaurants, professional offices, community businesses including bookstores, old-style bathhouses, and even some small town tearooms. All California hemophilia centers in the state are currently included. In the future, urban shooting galleries, street outreaches and massage parlors will serve as distribution points to males and female prostitutes.

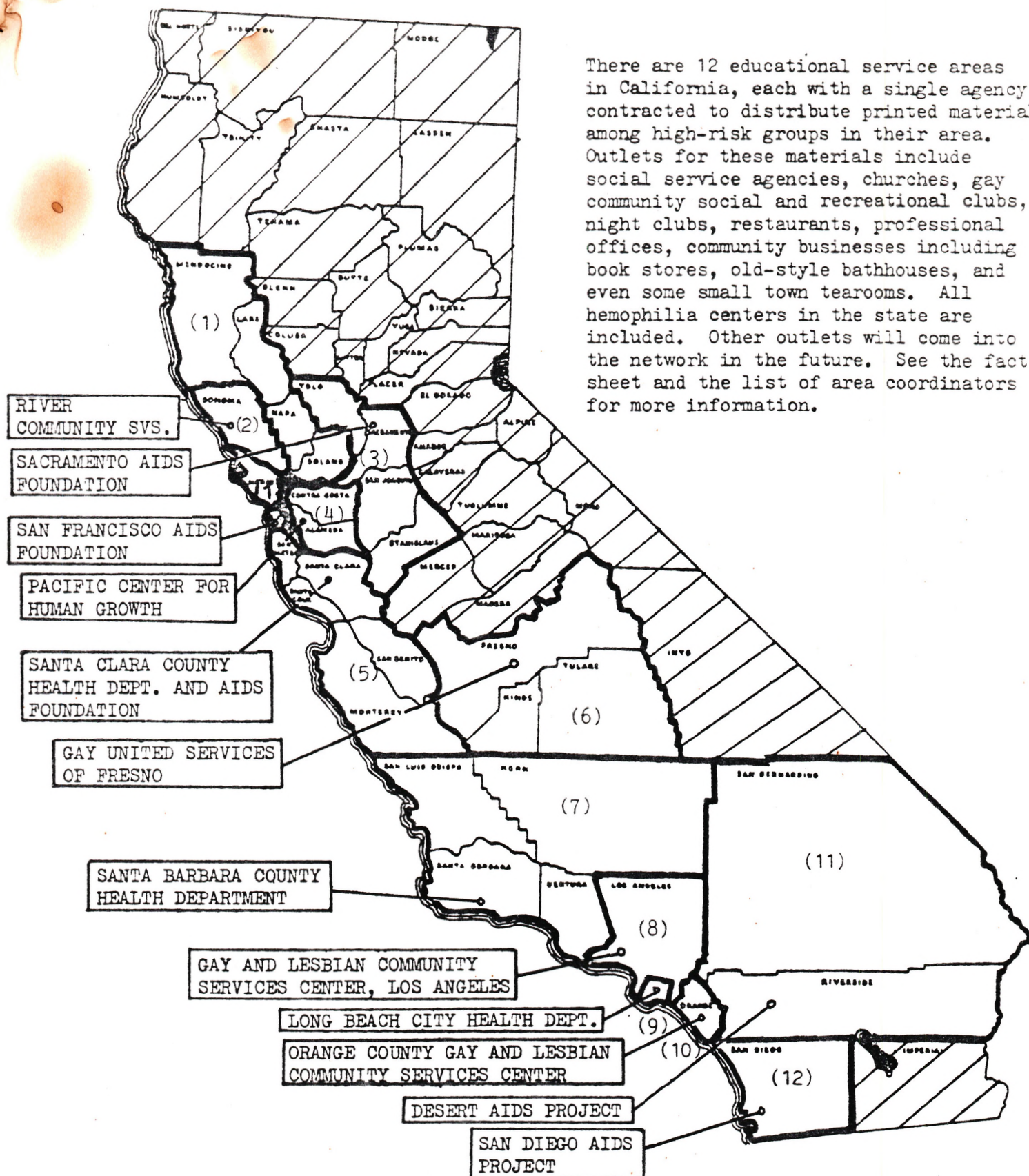
Collectively, the 12 contractors cover all 30 counties of the AIDS educational services area (see attached map). Seven contractors administer literature distribution services to more than one county. The system is operated with primarily volunteer assistance from local communities in cooperation with private business. The State supports coordinators in each of the 12 service areas to oversee the system.

The literature distribution activities of these contractors has been used in the past to make pamphlets, posters, and other educational materials accessible to high-risk groups. This role may be declining in importance for two reasons (e.g., saturation of the population with risk reduction messages and new emphasis on the use of the media). However, one use that continues to be important is to promote the workshops, forums, seminars, and other AIDS activities with flyers and announcements. A future use may be for the dissemination of urgent information to high-risk groups in a rapid and even fashion. Prognosis, research information, vaccine information, and prevention news can be disseminated using the system. This system is particularly important for high-risk individuals--healthy or ill--who may not routinely receive information in other ways.

Current problems for which there are only partial solutions include 1) the display and replenishment of materials in unfavorable environments such as dark, crowded bars, and 2) obtaining cooperation from a minority of influential business people.

LITERATURE DISTRIBUTION CONTRACTORS
BY SERVICE AREA

There are 12 educational service areas in California, each with a single agency contracted to distribute printed materials among high-risk groups in their area. Outlets for these materials include social service agencies, churches, gay community social and recreational clubs, night clubs, restaurants, professional offices, community businesses including book stores, old-style bathhouses, and even some small town tearooms. All hemophilia centers in the state are included. Other outlets will come into the network in the future. See the fact sheet and the list of area coordinators for more information.



LITERATURE DISTRIBUTION SYSTEM
SERVICE AREA COORDINATORS*

<u>Service Area</u>	<u>LDS Coordinator</u>	<u>Phone</u>	<u>Contractor</u>
1.	Lyn Paleo	(415) 864-4376	San Francisco AIDS Foundation
2.	Jim Stoll	(707) 887-2226	River Community Services
3.	Art McDermott	(916) 448-2437	Sacramento AIDS Foundation
4.	Jeremy Landau	(415) 548-8283	Pacific Center
5.	Dave Burgess	(408) 299-5858	Santa Clara
6.	Kay Vanderford	(209) 264-2436	GUS, Fresno
7.	Jerry White	(805) 967-2311	Santa Barbara
8.		(213) 464-7400	GLCSC, L.A.
9.	Ray Kincaide	(213) 427-7421	Long Beach
10.	Randy Pesquiera	(714) 534-0862	OCGLCSC
11.		(619) 323-2118	Desert AIDS Foundation
12.	Hal Frank	(619) 294-2437	San Diego AIDS Foundation

*Add 21 hemophilia treatment facilities serviced by the California AIDS Project.

CALIFORNIA AIDS PROJECT

Fact Sheet on the California AIDS Hot Line System

Through the contracted services of two California Acquired Immune Deficiency Syndrome (AIDS) agencies, the California AIDS Project maintains a statewide toll-free AIDS hot line system. The Northern California hot line, administered by the San Francisco AIDS Foundation, provides service to area codes 707, 916, 209, 408, and 415. The Southern California hot line, operated by the AIDS Project/Los Angeles, services area codes 619, 714, 213, 818, and 805. There are no gaps or overlaps in services. Both hot lines are promoted publicly, among health care providers, and in high-risk and patient groups. The system is operated primarily by community volunteers. In Northern California: 800-FOR-AIDS; in Southern California: 800-922-AIDS.

The California AIDS Project (CAP) hot line system is currently working well, providing AIDS-related information to over 4,100 callers monthly. At the same time, the system is evolving to meet the changing educational and referral needs of the communities they serve. In 1985, hot line operators will use the Computerized AIDS Information Network (CAIN) to obtain updated, reliable information electronically, thereby improving the quality and workload potential of the hot line system.

These improvements may become increasingly important in the future, when information on blood tests, the CDC redefinition of AIDS/ARC, the development of life-prolonging treatment modalities, and people-with-AIDS (PWAs) direct support referrals are needed.

REGIONAL HOTLINE SYSTEM
FY 1984-85

NORTHERN
CALIFORNIA
REGION

SAN FRANCISCO
AIDS FOUNDATION
800-FOR-AIDS

916

707

415

209

408

805

619

818

213

714

AIDS PROJECT/LOS ANGELES
800-922-AIDS

SOUTHERN
CALIFORNIA
REGION