

DEPARTMENT OF HEALTH SERVICES

CCLHO

California Conference of Local Health Officers

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May 22, 1987

TO: HEALTH OFFICERS
EPIDEMIOLOGY AND DISEASE CONTROL COMMITTEE
OTHER INTERESTED PERSONS

FROM: EILEEN M. EASTMAN, ^{JME}EXECUTIVE SECRETARY
CALIFORNIA CONFERENCE OF LOCAL HEALTH OFFICERS
OFFICE OF ADVISORY LIAISON

SUBJECT: DRAFT - AIDS DOCUMENTS

Enclosed are drafts of three documents for your review and comment. These documents are part of CCLHO's effort to describe the management of HIV infection at the local level. The documents enclosed are:

1. California Local Health Jurisdictions and the Management of Recalcitrant Patients with AIDS or AIDS Related Conditions
2. Epidemiologic Study/Mapping at the Local Level
3. Case Management of AIDS Patients

Please send your written comments by June 5, 1987 to:

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CALIFORNIA LOCAL HEALTH JURISDICTIONS AND THE MANAGEMENT OF
RECALCITRANT PATIENTS WITH AIDS OR AIDS RELATED CONDITIONS

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I. INTRODUCTION

The California Conference of Local Health Officers (CCLHO) recognizes that almost all persons who have Acquired Immunodeficiency Syndrome (AIDS) or AIDS Related Conditions (ARC) will assume responsibility for the prevention of Human Immunodeficiency Virus (HIV) transmission. It has been demonstrated that once informed about how to prevent infection and educated about how to prevent infection, people with AIDS and ARC will modify their behavior so as to prevent transmission to others.

These guidelines are prepared to assist the Local Health Officer when he/she is confronted with that rare individual with AIDS or ARC who knows he/she is infected with HIV virus, knows how transmission is accomplished and continues to knowingly and willfully engage in high risk activities which are likely to expose others without the knowledge of those exposed. The guidelines included here describe the variety of interventions that the Local Health Officer should consider when he/she plans to change the dangerous and reckless behavior of such a recalcitrant person with AIDS or ARC.

Currently, and until research produces effective treatment and/or immunizing agents, we must depend upon community and individual education to reduce the spread of HIV infection. Educational efforts to reduce the spread of HIV by encouraging reduction of behaviors with a high risk of transmitting HIV is underway in most communities. These efforts are working. Local Health Officers must be particularly careful that any action taken in regard to the recalcitrant patient not interfere with these highly productive activities or be perceived as a barrier to persons with AIDS or ARC who seek care.

II. PUBLIC HEALTH CONCERN

Persons with AIDS/ARC who may be at risk of transmitting AIDS/ARC should be educated about how to prevent the spread of HIV infection to others. These educational efforts must be individualized to fit the person's specific personal habits and can be reinforced by support groups and others. As long as persons agree to and understand how to prevent the spread of infection, the Local Health Officer need take no further actions. The responsibility of the Local Health Officer to intervene in any case of AIDS/ARC is present only when there is a valid threat to the public health. Action is only appropriate in cases in which the individual with AIDS/ARC knows he/she is infected, knows how transmission is accomplished and continues to knowingly and willfully engage in high risk activities which are likely to expose others without the knowledge of those exposed.

III. Definition of Terms

Acquired Immune Deficiency Syndrome (AIDS): Relates to a clinical condition which is part of the spectrum of disease caused by the Human Immunodeficiency Virus (HIV) and is defined by the Centers for Disease Control (CDC).

AIDS Related Condition (ARC): Refers to a number of different CDC classifications which are part of the spectrum of disease of the HIV infection. These include Group III and those parts of Group IV which do not meet the strict CDC definition of AIDS.

Recalcitrant Patient : A person with AIDS or ARC who knowingly and willfully engages in high risk behavior after being informed of the risk to the public of such behavior.

Quarantine: Title 17 of the California Administrative Code 2520 states: "Quarantine is defined as the limitation of movement of persons or animals that have been exposed to a communicable disease for a period of time equal to the longest usual incubation period of the disease, in such manner as to prevent effective contact with those not so exposed. If the disease is one requiring quarantine of the contacts in addition to isolation of the case, the local health officer shall determine the contacts who are subject to quarantine, specify the place to which they shall be quarantined, and issue instructions accordingly. He shall insure that provisions are made for the medical observation of such contacts as frequently as necessary during the quarantine period." (underlining added)

Isolation: Title 17 of the California Administrative Code 2515 states: "Isolation is defined as separation of infected persons from other persons, for the period of communicability in such places and under such conditions as will prevent the transmission of the infectious agent."

Modified Isolation: If the disease does not require strict isolation from all contact with other persons, the local Health Officer shall issue appropriate instructions of modified isolation, prescribing the isolation technique to be followed. 17 Cal. Adm. Code 2518.

Order for Examination: This is an order for a person to appear at a designated site in order to establish the facts. 17 Cal. Adm. Code 2512.

IV. INTERVENTIONS

Most individuals will willingly comply with reasonable requests to modify their behavior so that they reduce the likelihood of infecting others. Presented below are a number of interventions possible in helping individuals to reduce risk behavior.

- A. Community Education: All persons must be made aware of AIDS, the transmission of HIV, and risk reduction behaviors. All persons need to be encouraged to practice risk reduction routinely. Community education remains the most important tool in stopping the epidemic.
- B. Individual Education: Persons with AIDS/ARC must be intensively educated about risk reduction. Specific risk activities must be discussed, so that the individual understands what she/he must do in order to prevent infecting others. Equally important is education about what activities do not pose a risk of infection to others.
- C. Intensive Counseling/Peer Pressure: Persons who know of their infection, and how it is spread, and yet continue at-risk behaviors without informing others of their infection should receive intensive education/counseling in order to ensure they truly understand their disease and the potential risk of infecting others. If the individual is involved in a group such as a support group, and he/she is willing to discuss his/her infection and activities, the group can be a useful tool in encouraging risk reduction.
- D. Rehabilitation: Prostitutes and others who gain financially through at-risk activities may require job counseling or employment opportunities outside of prostitution in order to assist them in their efforts to reduce at-risk behaviors. Condoms must be readily available for all persons willing to utilize them.
- F. Drug Treatment Programs: Persons who are at risk of infecting others through the sharing of needles during intravenous drug use should be referred to treatment resources for their drug use. Recognizing that opiate use constitutes only a portion of all intravenous drug use, the availability of an adequate number of treatment

slots for persons with AIDS/ARC should be assured by state and local treatment programs. The availability of these programs may assist in modifying the behavior of an IV drug user with AIDS/ARC.

All of the above interventions necessary to encourage risk reduction behavior should be available in every local jurisdiction. Consultation from experts in the field of risk behavior are available at the local and state level, and can be utilized to describe the best approach to intervention in a particular case.

V. FAILURE OF INTERVENTIONS

Unfortunately, there are likely to be a few individuals in whom all interventions fail, and who continue to knowingly and willfully engage in risk behaviors which may infect others without the knowledge of those others. These individuals are termed "recalcitrant." Their recalcitrance is not established due to the presence of AIDS/ARC, but due to the fact that they knowingly and willfully continue to behave in a way which puts unconsenting others at risk of infection. These recalcitrant individuals present a threat to the public health. The Surgeon General¹, the Institute of Medicine, National Academy of Sciences², and others^{3,4} agree that while they oppose isolation or quarantine of persons with AIDS/ARC, that compulsory measures may need to be used in the rare case of a recalcitrant patient.

Several Local Health Officers have had cases of recalcitrant individuals referred to them for possible legal action under current state law. In every case, the local jurisdiction has been able to intervene in such a manner as to not require legal enforcement activities in order to gain compliance from the person referred. The referrals have come from the criminal justice system, from the community, and from medical practitioners. In each case, successful compliance has been accomplished voluntarily. Legal action was not required because education and community support services succeeded. The response must follow current disease control statutes, provide for confidentiality, and assure due process of law for potentially affected individuals.

VI. CONSIDERATIONS

In responding to a request to utilize legal authority in the case of an alleged recalcitrant individual with AIDS/ARC, the Health Officer must consider a number of different issues.

- A. Facts of the Case: There is a potential for abuse of any system, and the Health Officer must be aware that there is prejudice against some groups which include individuals at-risk and against persons with AIDS/ARC. The Health Officer must determine that the facts of the case warrant his/her involvement beyond interventions mentioned above, and that the individual is truly

recalcitrant. If a request for action comes from the criminal justice system, it is hoped that it will have already established the facts which will permit the Health Officer to determine whether legal intervention is warranted. The facts must establish that the individual does indeed have AIDS/ARC, is behaving in a manner which threatens the public health and that interventions mentioned previously have been tried without success. If the referral comes from a source which has not established the facts, the Local Health Officer must obtain the information to establish these facts.

- B. Behavior, Not Disease: It should be repeatedly stressed that any possible legal action on the part of the local Health Officer should be as a result of specific recalcitrant behavior(s), and not as a result of the presence of disease. Existing CDC recommendations, if followed, adequately protect the health of the public. It would be only if those recommendations are knowingly and willfully violated that the local Health Officer might consider legal action. Any legal action which may be considered must be in terms of changes in behavior.
- C. Reason for Exercising Authority: The Health Officer must have a clear idea of the intended outcome of any legal action which may be considered. He or she must document that all other possible interventions have failed, and be able to explain why legal action is necessary in the individual case. If the intended action is to add legal authority to a prescribed program of risk reduction, that should be stated. An additional consideration is how far the Health Officer will pursue a legal course. If the first step fails, will step two be taken, etc.
- D. Due Process of Law: Requests being made to local jurisdictions are for the application of current laws to alleged recalcitrant persons with AIDS/ARC. Although these laws do not contain specific provisions for due process of law in their application, such provisions are constitutionally required. We strongly urge every Health Officer to add due process of law to his/her jurisdiction's policies and procedures. The California Conference of Local Health Officers (CCLHO) requests that the Department of Health Services establish statewide guidelines for due process of law. Some counties have established a due process policy which can serve as a model.
- E. Frequent Review: Any possible legal action taken must be frequently reviewed by the Health Officer. Any legal action taken would be the result of the specific behavior(s) of individuals, and would be specific to the behavior rather than to the disease. Once an individual changes his or her behavior so that he or she no longer presents a threat to the health of the public, any legal action should be dropped.

- F. Consultation: Consultation from experts in the field of specific risk behavior should be sought to try to identify any interventions short of legal action which may be helpful in dealing with a recalcitrant individual. Additionally, consultation from Health Officers in counties more experienced with AIDS/ARC should be sought. Those counties have dealt with requests to act in cases of alleged recalcitrant individuals and can provide valuable consultation in dealing with a request. The Health Officer is encouraged to form an advisory panel of local experts to review any request. Such review must assure confidentiality of information about all individuals involved.
- G. Negative Program Impact: A very serious consideration is the negative effect that any legal action against recalcitrant individual with AIDS/ARC may have. The concern is that any move to invoke current laws (regardless of justification) would frighten all persons with AIDS/ARC, and that non-recalcitrant persons would not seek needed medical attention, fearing legal action. This is a serious concern, and must be carefully weighed prior to any possible legal action is taken. Discussions of this issue should occur between the Health Officer and community leaders, especially the gay/bisexual community, and the intravenous drug abuse provider community. Those discussions should be held prior to any specific request.
- H. Resource Exhaustion: A related concern is that of resource exhaustion. Some persons believe that local jurisdictions would exhaust valuable resources in situations involving the invocation of current laws against any individual, and that those same resources would be better put toward community and individual education, and other nonlegal interventions. This is a consideration in deciding how to respond to any request for evaluation of a particular case. However, it must be recognized that requests for action come from outside the health jurisdiction (rather than from within) and some response must be made. In the most cases the request does not justify any involvement of the legal authority of the Health Officer: either the facts show the individual in question to not be knowingly and willfully behaving in a manner which endangers the public health, or nonlegal interventions enables the individual to change his/her behavior. However, the local Health Officer must consider how he/she will respond in the case of a person who is truly recalcitrant, and for whom no nonlegal interventions seem to work. Each jurisdiction must decide how to proceed if all nonlegal efforts fail and an individual remains recalcitrant. Planning for this possibility, including discussions of the issues within the community, will save time and resources if action is required.
- I. Is It Worth It? Ultimately, the Health Officer must determine what, if any action should be taken. After all nonlegal interventions have been tried, consultation has

been obtained, and if a recalcitrant individual continues to act so as to present a threat to the public health, the Health Officer may find it necessary to consider legal action. Such action should be taken only after careful consideration of issues presented above. (To move to invoke current law to reduce the public health threat caused by the actions of one or a very few individuals will do no overall good if other aspects of the local jurisdiction's AIDS programs suffer disproportionately. The affect of such an action may do more overall harm than good.)

- J. Mental Competence: It must be recognized that some persons with the AIDS/ARC engaging in activities which might infect others might be mentally incompetent to understand the danger their activities pose to others. In cases in which there is a question of a person's competence to control his/her behavior, psychiatric examination is an appropriate part of the examination of the individual. The psychiatric examination and its outcome are adjuncts to, not a replacement of interventions and legal actions related to the control of communicable disease. The responsibility for disease control is that of the Local Health Officer. There are a few individuals who are so gravely disabled that they are conserved, or otherwise become the responsibility of the local mental health programs. Even in these cases, the Local Health Officer must retain responsibility for directing steps and establishing procedures to reduce behavior which might spread HIV infection.
- K. Judicial Remedy: The possible legal actions discussed below constitute application of current state law. Judicial remedy may be sought by individuals at any point in the process. Once any official action is taken on the part of the Local Health Officer, affected individuals may seek injunctions or other activities through the judicial system.

VII. POSSIBLE LEGAL ACTIONS RELATING TO THE RECALCITRANT INDIVIDUAL

Legal action taken by the Local Health Officer to alter an individual's at-risk behavior must be considered only after the above mentioned interventions have been offered or tried, and the recalcitrant individual continues to behave in such a manner as to pose a threat to the public health. Legal action should not apply to individuals engaging in consensual acts in which the other individual(s) are aware of risk. All persons should be advised to refrain from activities which may put them at risk of acquiring infection with the HIV, and therefore be able to make choices about their own activities. Any proposed action would only be appropriate in cases in which individuals who are known to have AIDS/ARC intentionally and willfully behave in high risk activities which may expose others without the knowledge of those exposed.

Actions which exist in current state law and regulation for consideration by the local health jurisdiction include Order for Examination, Order of Modified Isolation, Order of Strict Isolation, and Quarantine. Of these possibilities, quarantine is totally inappropriate: it pertains to the limitation of movement of a person exposed to a communicable disease, not to the behavior of a person known to be capable of infecting others. We do not recommend that the Local Health Officer issue an Order of Strict Isolation. Any order restricting the movement of an individual with AIDS/ARC should be issued by the judicial system and not through administrative law. The Health Officer may consider two possible actions--the Order for Examination and the Order of Modified Isolation.

- A. Order for Examination: The purpose of the Order for Examination is to establish facts in a case referred to the Local Health Officer for action to invoke current laws. The first step in the consideration of any action must be to establish the facts. Most referrals for local jurisdiction legal action not justified from the standpoint of protecting the public health. The Order for Examination may be necessary to evaluate a referral in rare cases. It orders a person to appear for examination. Its use would provide for an opportunity to interview an alleged recalcitrant individual in order to assess the individual's infection, his/her knowledge and understanding of risk behaviors, how to reduce risk, and his/her willingness to voluntarily comply with risk reduction activities. During the interview, the individual can be informed of options available to the Health Officer should the individual be unwilling to comply in reducing the risk of infecting others. The hoped for outcome of the interview will be that the individual increases his/her knowledge of how to prevent the possible transmission of infection and agrees to engage in the discussed risk reduction program. If that is the case, further legal actions are not necessary. If the individual fails to respond to an Order for Examination or does not agree to behave in such a manner as to no longer present a threat to the public health by knowingly and willfully acting so that he/she might infect others, further action should be discussed with the Local/County Counsel.
- B. Order of Modified Isolation: The purpose of this action in the case of a recalcitrant person with AIDS/ARC would be to specifically and legally define desired activities, or to prohibit undesired activities. This Order should concern definition or limitation of activities, and not of movement. A Modified Order of Isolation might prescribe counseling, and/or prohibit certain at risk behaviors such as high risk sexual practices, sharing of unclean I.V. drug paraphernalia, etc. If the Order is violated, the individual is guilty of a misdemeanor under current law, and the District Attorney may take action against the individual.

- C. The Judicial System: If, with the failure of the above measures, the Local Health Officer finds it necessary to consider further action related to the AIDS/ARC patient, he/she should request that his/her local District Attorney charge the recalcitrant person with AIDS/ARC with (1) refusal to comply with a modified isolation order (Section 3351, Health and Safety Code) or (2) a violation of Section 3353 of the Health and Safety Code. This Section states that "any person afflicted with any contagious, infectious, or communicable disease who willfully exposes himself, and any person who willfully exposes another person afflicted with such disease, is guilty of a misdemeanor." This Section appears to make it a misdemeanor to willfully expose an individual to a communicable disease. Action on either of these charges will assure that the individual's situation is considered in the judicial system rather than in the administrative law system, thereby assuring the individual of due process of law in any further actions.

References:

1. Surgeon General's Report on AIDS
2. Confronting AIDS: Directions for Public Health, Health Care, and Research. Institute of Medicine. National Academy of Science. National Academy Press, Washington, D.C. 1986, Page 130
3. AIDS Quarantine: The Legal and Practical Implications. Nancy L. Ford, J.D., and Michael D. Quam, Ph.D., M.P.H. Center for Legal Studies, Sangamon State University, Springfield Illinois, 1986, Prepublication copy, Page 36
4. Francis D, Chin J: Prevention of Acquired Immunodeficiency Syndrome in the United States. JAMA 257:1357-1365

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CCLHO PAPERS ON HIV INFECTION CONTROL:
EPIDEMIOLOGIC STUDY/MAPPING AT THE LOCAL LEVEL

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I. BACKGROUND

The study of epidemics in a community involves the attempt to describe the segment of the population that is ill, identify those who may be at risk of future illness or infection and define the mechanism of spread of the disease in question. In the case of a widespread epidemic such as AIDS, it is necessary to create a system of epidemiologic surveillance extending from the local community to the State and National level. Surveillance is the systematic collection of data on cases of disease in the population and on deaths due to the disease. The goals of surveillance at the local level are then twofold: to contribute to the nationwide system, and to identify any significant way in which the local community differs from the national or regional pattern.

II. RATIONALE

The information gathered through epidemiologic surveillance is used for three broad purposes: first, to plan strategies and interventions to interrupt the spread of the epidemic; second, to determine the kinds and quantities of health services that will be required to assist those who are ill; third, to monitor/evaluate the effectiveness/success of prevention efforts that are established as the epidemic progresses.

At the present time, with little prospect for a vaccine to prevent spread of the virus or of a drug to treat the illness, the principal strategy for intervention is education for behavior change. Thus, the information gathered from surveillance is used, for example, to focus educational messages for a particular community and to select target groups for the messages. It should be noted that important uses of the information are to increase community awareness of the epidemic and to provide objective and scientific information about its impact to the public and to policy makers.

III. HIV SURVEILLANCE: EXISTING DATA SOURCES

Surveillance of a communicable disease usually begins with counting of cases of the most severe illness or of death due to the illness. In the AIDS epidemic, the syndrome called "AIDS" was in fact created as a definition for epidemiologic reporting purposes. We have subsequently learned that there is an entire spectrum of illness associated with the causative agent of AIDS, i.e., Human Immunodeficiency Virus, or H.I.V. Thus, we have established a system of surveillance that is currently being modified, and which will continue to expand.

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A. Surveillance of Advanced Disease: AIDS Case Reporting

Definitions: AIDS is a reportable condition under California law, and physicians must report cases through local health departments to the State. The Center for Disease Control's 1983 definition of AIDS (Appendix I) is currently used, and local jurisdictions are responsible for ensuring that the CDC's detailed case reporting form is completed to provide clinical and demographic data on each case. The definition of AIDS is currently being revised and expanded, and when the definition changes, local health jurisdictions must play a role in informing physicians of this, as well.

Tasks: To ensure completeness and accuracy of reporting, local health departments must have established good working relationships with hospitals and practicing physicians. Special effort may be required to ensure that physicians understand the definition of AIDS and the somewhat more complex reporting procedures. This may require both initial and ongoing orientation of the medical community through hospital staff presentations, newsletters to physicians and/or individual contacts with their nursing and clerical staff. It is especially important to work with hospital infection control nurses in setting up reporting systems. In larger communities, it may be helpful to work with "sentinel physicians", that is those who see significant numbers of AIDS patients and who are willing to make special efforts to ensure complete and accurate case reporting.

Data collection/analysis: Each local jurisdiction should retain copies of case reports and tabulate local data weekly or monthly or as often as needed. Although larger jurisdictions may have automated systems to do this, a simple monthly manual tabulation of data on the case report form is remarkably useful. Sample formats are shown in Appendix II, III and IV. Each jurisdiction will want to compare its distribution of risk factors with State, regional and national data, and to look for unusual patterns in terms of age, sex, ethnicity, behavioral risk factors or residence. Mapping of cases by census tract, or city of residence, may be useful in areas with large case loads, both for assessing needs for health services and for targeting educational efforts. An example of such mapping is given in Appendix III, page d.

Data dissemination: It is essential to provide summaries of these data both to those involved in reporting (physicians and hospitals) and to the community at large. This may be done on a monthly, quarterly or annual basis, depending on the size of the community, but it is essential to provide feedback to those who are doing individual case reports, and to let the community at large know what is being learned about aspects of the epidemic unique to a particular area. Some communities have found that this may be a time consuming task because many reporters are not familiar with the process of interpreting numerical data; it is especially important to have trained staff available to answer

questions and to assist in distinguishing between significant and spurious trends.

B. Surveillance of ARC

Although the Centers for Disease Control have provided definitions for the less severe forms of HIV illness, systematic reporting or surveillance have not been conducted in California. It may occur within the next few years, however, and it would be expected that the process would parallel or be based on the AIDS system described above. The same considerations related to data analysis and dissemination will apply if ARC surveillance is instituted.

C. Data on HIV Infection

It is now well established that there may be a long and variable latency period between the time of exposure to HIV and the onset of AIDS or ARC as clinical syndromes. During this time the individual is described as HIV infected, and the presence of infection can be detected by the presence of HIV antibody.

There is no reporting or surveillance method contemplated for HIV infection in California, for reasons discussed elsewhere in this series of papers. Nevertheless, there are several potential sources of data on HIV infection in special populations, and these are of great importance even in the small community.

Alternate Site Test data: The Alternate Test Site System offers an opportunity to assess HIV positivity in a self-selected segment of the population who have perceived themselves to have had high risk of exposure. During this anonymous testing, data are collected on age, ethnicity and risk behaviors. Even when the numbers of tests being conducted are small, it is worthwhile to describe the positivity rates for the various subsets of the community, and to compare this to regional or national data. A manual tabulation of data can be done in a format such as Appendix II, pages a and c, and these data can be compared to findings reported in California Morbidity, from the State AIDS Program, or from MMWR.

Blood bank data:

Local jurisdictions should make every effort to obtain statistical summaries from blood banks serving them. This provides information on individuals specifically screened to have no identified risk of exposure to HIV infection. If prevalence increases in such low-risk individuals, every effort should be made to investigate such cases. Currently, blood banks report a range of 0.02-0.05% seropositivity.

Confidential testing data:

These data represent individuals who have had high risk exposure and whose health care providers have agreed to test or have

advised testing. Although such data have not been available in the past, with recent upsurge in interest in confidential testing, an effort should be made to obtain summary data, and to organize and present data on positives by risk behavior.

Data from military installations:

Those communities having significant military populations should attempt to gather data that are available from local or regional military authorities. Case counts, antibody testing data and other special studies may have direct relevance for the military families living in the community as well as for the civilian population.

D. Mortality Data

Death certificates, hospital and physician reports can provide the basis for linking AIDS case reports with subsequent mortality. It is essential to use a combination of these methods as any one may not be reliable. Follow-up data on mortality is reported to State and Federal government and should be included in data summaries provided to practitioners and the community. In larger communities, it may be worthwhile to monitor the interval between initial case reports and death, both to evaluate changes in stage of diagnosis and reporting of the disease and to evaluate length of survival following diagnosis and treatment.

E. Special Issues in Reporting

The issue of confidentiality has been discussed elsewhere, but has never been more important than in the AIDS epidemic. The most likely source of error in the data related to AIDS surveillance is underreporting, and this in turn is most likely to be due to fears about breach of confidentiality. While local health departments have been successful in preserving privacy and confidentiality in communicable disease reporting for many years, it is essential for each jurisdiction to thoroughly review its procedures for receiving, processing, reporting and storing records related to the AIDS epidemic. Provisions of California Health and Safety Code (Appendix V) should be made familiar to all clinic and clerical staff, and staff should keep abreast of all changes in the law related to confidentiality. The local health department also is viewed as the source of this information for the practicing medical community, and may be required to regularly provide information on this topic to hospital staffs, medical societies and other groups. Finally, a continuous effort should be made to assess the completeness and reliability of all the data being collected relating to AIDS, whether through independent studies, through comparison with regional trends or through periodic evaluation of samples of data. In cases where gaps or weaknesses in data are detected, surveillance systems may need to be changed or refined.

VI. OTHER DATA SOURCES

A. Other Sexually Transmitted Disease

Reporting of other communicable diseases which may be viewed as surrogate markers of disease activity including sexually transmitted diseases and Hepatitis B may provide useful information to the progress of the AIDS epidemic, to the extent that they provide indicators of the level of risk-taking behavior in the community or in particular segments of the community. Such data can be organized in terms of trends in disease rates (e.g. gonorrhea or syphilis) in age or sex-specific groups (e.g., women, single men) over the decade that includes the appearance of the AIDS epidemic. Similarly, the trends relating to Hepatitis B in IV-drug related cases may provide an indicator of change or lack of change in practices related to IV drug use. Since these data are already available in most local communities, they can be organized and analyzed with relatively little additional effort. Provision of this information back to the community at large may play a significant role in supporting or modifying the prevention strategies that are underway.

B. Contact Notification as a Data Source

Findings of contact notification studies may provide examples of heterosexual transmission or may provide local evidence of how uncommon such transmission is. It may also be applied to homosexual and IV drug populations in areas where the majority of individuals are not infected.

C. Basic Demographic Data - Denominators

In order to develop rates related to some aspects of AIDS, it is necessary to use denominators, and much of these data are available through local planning and economic development agencies. However, for most communities, accurate data on key variables such as the extent of IV drug use or sexual orientation are not available, and it is not likely to be worthwhile trying to develop estimates.

D. Comparisons with National or Regional Data

Local intervention plans should be developed with specific reference to similarities and differences between local data and State/Regional/National data. In smaller communities where little local data are available, some caution should be exercised in interpolating from National data for purposes of planning local programs. A better approach would be to seek data from one or several similar small communities, selected for comparable demographic and socio-economic factors.

E. Special Targeted Studies

For many communities, it may be possible to conduct special studies of selected populations at points in time. These may

include seroprevalence studies (e.g. prevalence of HIV positivity in STD clinic populations, jail populations, prostitutes, IV drug users) in order to periodically monitor spread of HIV infections in these communities. In conducting such studies in California, it is currently necessary to obtain written consent of the subjects, and it is desirable to conduct the studies under the auspices of a scientific institution that has a human subjects review process.

Problems with such studies include but are not limited to: 1) Difficulty in recruitment secondary to fears surrounding breaches in confidentiality and access to medical records, 2) In jail/prison populations, knowledge of antibody status by other inmates has provoked death threats, 3) Knowledge by the local health department of antibody status in prostitutes poses some ethical and potential legal issues.

Blind seroprevalence studies have been recommended to identify populations with increased levels of HIV infection at a point in time, and may be useful for this purpose where a sufficient numbers of serum specimens are available to determine level of infection. Such populations may then be targeted for voluntary, confidential testing. However, this type of study is not appropriate on an ongoing basis, and it poses ethical problems because the anonymity inherent in the method prevents notification of any positives identified. Any such study should thus be carefully reviewed by a human subjects review committee prior to implementation.

In larger communities it may be possible to conduct studies on the extent of risk-taking behavior. These are analogous to the KAP studies, (Knowledge, Attitude and Practice) that have been used extensively in the family planning field over the past 30 years. These studies may be used to evaluate both the effectiveness of current educational and prevention strategies and to develop new approaches.

Regional studies may be practical in situations where one county alone cannot mount the resource for "research" on special populations. This may become possible and useful where several counties share common special populations, and where national and statewide data are not applicable. An example of such a study might be one on knowledge, attitudes and practices among single male, seasonal agricultural workers in the central valley. There is significant IV drug use in this population, but it almost certainly involves different patterns and practices from those studied on the Eastern seaboard in Eastern cities and in West Coast inner cities. Findings from such a study should be shared with rural counties throughout California.

V. STUDIES ON HEALTH CARE: NEEDS, COSTS AND ORGANIZATION

Studies of implications of the AIDS epidemic for health care will vary greatly according to the size of a community, and according to the time frame that is attempted. While many of the costs for such care

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will ultimately be borne by the State and Federal governments, and thus large-scale and long-term projections are already being conducted at these levels, the local policy makers will want to be aware of workload and organizational implications at the community level.

The most important variable, expected case load, is also one of the most difficult to project on a small scale. Case load modeling studies on the national and regional levels demonstrate the pitfalls in making estimates of the epidemic curve more than a few years into the future. In fact, models used by different agencies and jurisdiction are currently producing dramatically different projections of caseload in the future. In choosing any one model or method, the local jurisdiction should be aware that others exist and may produce different results. Nonetheless, the local community needs to estimate numbers of new cases for purpose of health service planning for three to five years in advance.

In addition, an attempt should be made to determine where patients are receiving outpatient, inpatient and extended care (or hospice) care services, and how these services are being financed. Home health services, laboratory services, counseling and family support may also be part of such an inventory. In those communities that establish case management systems for assisting patients with AIDS, some very valuable information will become available on all aspects of medical and support needs of the patient, and this can also be used in planning and providing such care.

RJM:jh

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CENTERS FOR DISEASE CONTROL: DEFINITION OF AIDS

For the limited purposes of epidemiologic surveillance, CDC defines a case of "acquired immune deficiency syndrome" (AIDS) as a person who has had:

- A. a reliably diagnosed disease that is at least moderately indicative of an underlying cellular immune deficiency, but who, at the same time, has had:
- B. no known underlying cause of cellular immune deficiency nor any other cause of reduced resistance reported to be associated with that disease.

Diseases at least moderately indicative of underlying Cellular Immune Deficiency:

These are listed below in 5 etiological categories: A) protozoal and helminthic, B) fungal, C) bacterial, D) viral, and E) cancer. Within each category, the diseases are listed in alphabetical order. "Disseminated infection" refers to involvement of liver, bone marrow, or multiple organs, not simply involvement of lungs and multiple lymph nodes. The required diagnostic methods with positive results are shown in parenthesis.

A. Protozoal and Helminthic Infections:

1. Cryptosporidiosis, intestinal, causing diarrhea for over 1 month, (on histology or stool microscopy)
2. Pneumocystis carinii pneumonia, (on histology, or microscopy of a "touch" preparation or bronchial washings)
3. Strongyloidosis, causing pneumonia, central nervous system infection, or disseminated infection, (on histology);
4. Toxoplasmosis, causing pneumonia or central nervous system infection (on histology or microscopy of a "touch" preparation)

B. Fungal Infections:

1. Aspergillosis, causing central nervous system or disseminated infection (on culture or histology)
2. Candidiasis, causing esophagitis (on histology, or microscopy of a "wet" preparation from the esophagus, or endoscopic findings of white plaques on an erythematous mucosal base)
3. Cryptococcosis, causing pulmonary, central nervous system, or disseminated infection (on culture, antigen detection, histology, or India ink preparation of CSF)

C. Bacterial Infections:

1. "Atypical" mycobacteriosis (species other than *M. tuberculosis* or *M. lepra*), causing disseminated infection on culture)

...continues

AIDS MONITORING STATISTICS

3/27/87

HIV CASE REGISTRY

As of 3/25/87:

396 AIDS cases of whom 237 have died

202 ARC cases of whom 7 have died
75 have gone on to AIDS

506 ARF cases of whom 13 have died
26 have gone on to AIDS
8 have gone on to ARC
1 ruled out

105 HIV + only of whom 6 have died
1 has gone on to AIDS
3 have gone on to ARF

ALTERNATIVE TEST SITE

As of 1/31/87:

	CUMMULATIVE			JANUARY 1987		
	#	# +	% +	#	# +	% +
	---	---	---	---	---	---
Tests done	5,244	(685+)	13.1%	523	(41+)	7.8%
Homosexual	2,101	(532+)	25.3%	117	(23+)	19.7%
Bisexual	659	(77+)	11.7%	60	(9+)	15.0%
I.V. Drug User	635	(70+)	11.0%	65	(9+)	13.8%
Transfusion recipient	167	(17+)	10.2%	16	(2+)	12.5%
Multiple partner heterosexual	750	(12+)	1.6%	145	(3+)	2.1%
Hemophiliac	3	(1+)	33.3%	0	(0+)	0.0%
No known/admitted risk factor	531	(8+)	1.5%	64	(0+)	0.0%

JAIL TESTING PROGRAM

As of 3/24/87:

1300 tests

32 positives (2.5%)

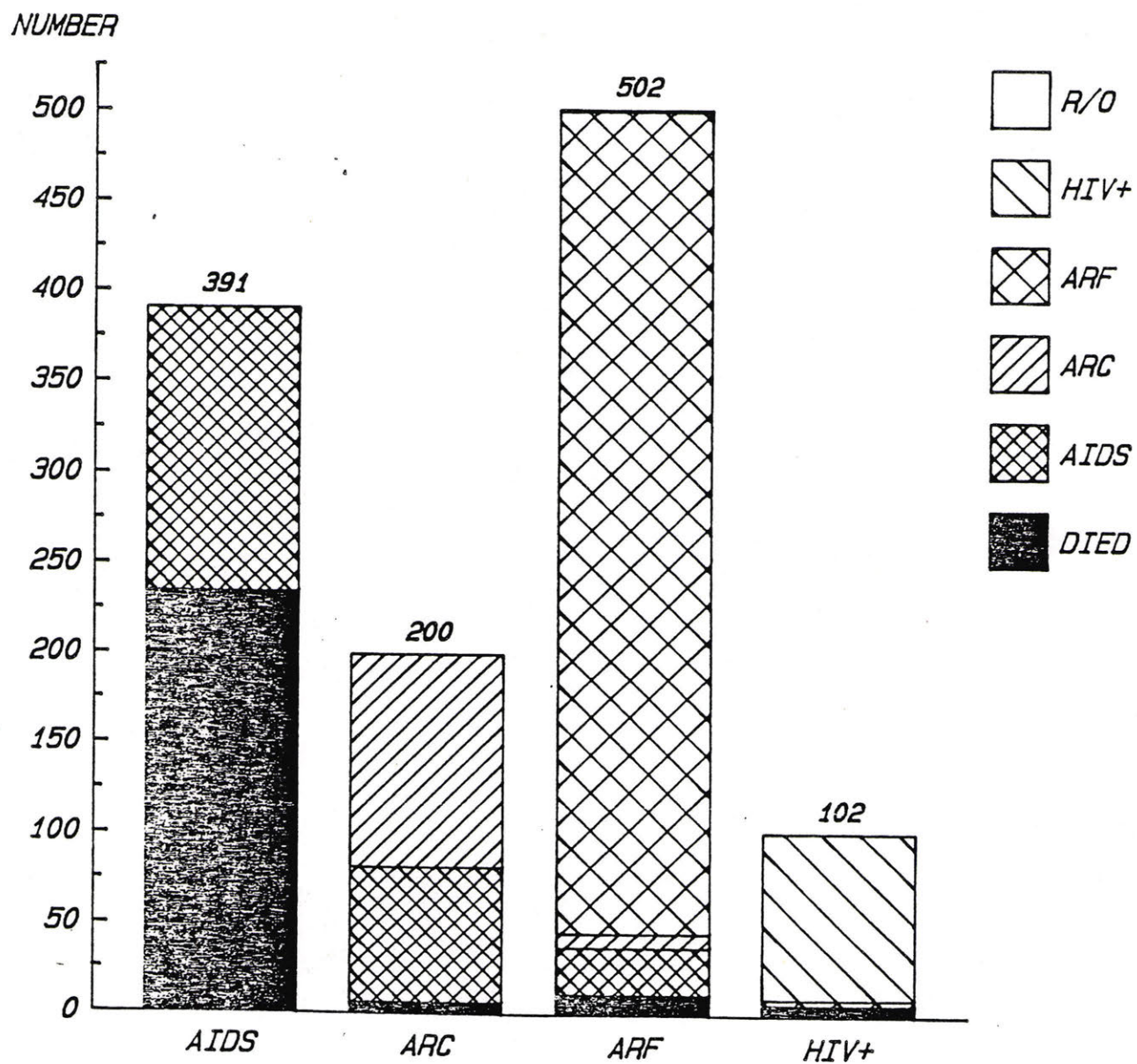
of which 3 are convertors from negative to positive

RED CROSS BLOOD SCREENING

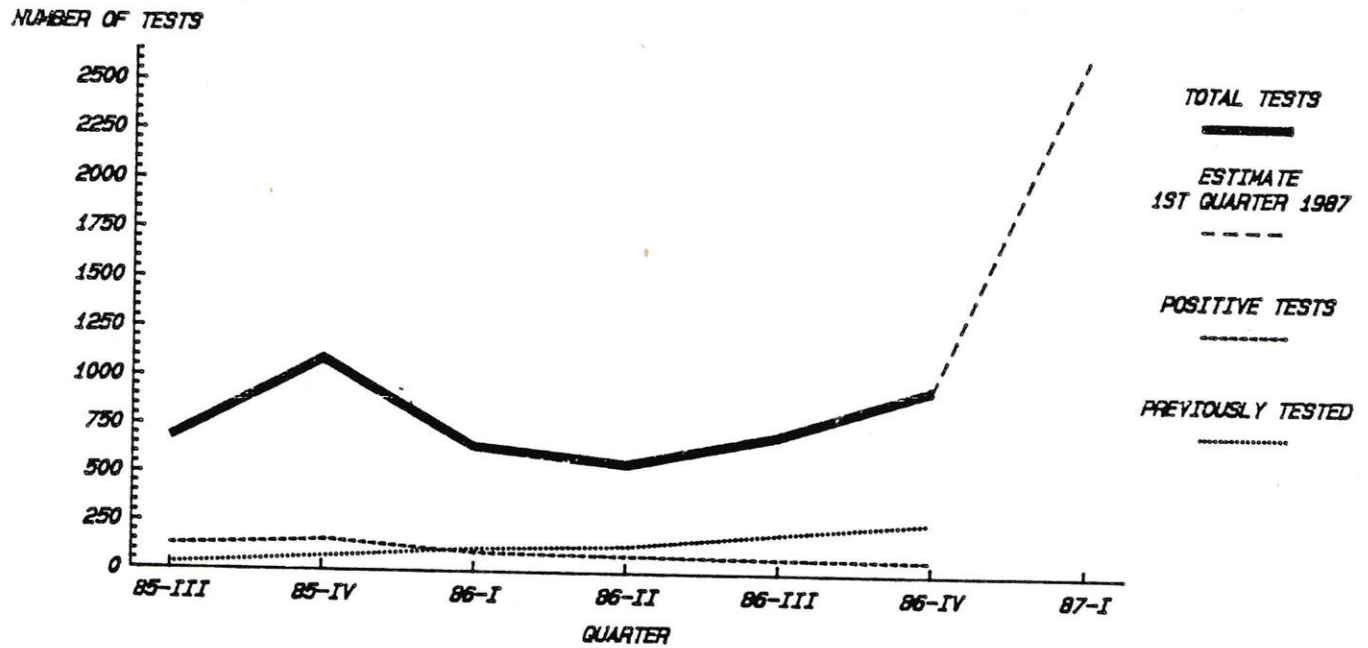
As of 2/28/87:

3/85 - 7/86	110,000 units	41 positive	37.3+/100,000 units
8/86 - 12/86	40,000 units	6 positive	15.0+/100,000 units
1/87 - 2/87	19,500 units	2 positive	10.5+/100,000 units

*COUNTY OF ORANGE HIV CASE REGISTRY
CASES THROUGH 3/18/87 BY DIAGNOSIS*

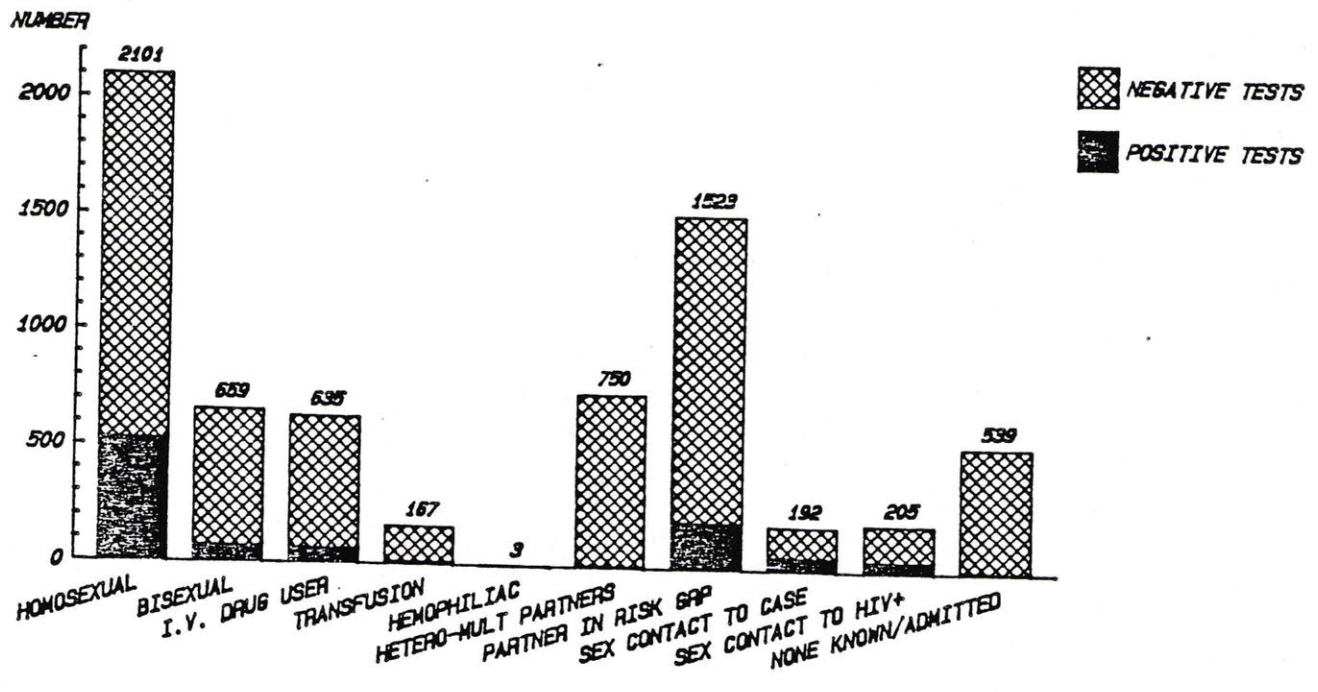


ALTERNATIVE TEST SITE SUMMARY STATISTICS
 PERSONS TESTED THROUGH 12/31/86
 HIV ANTIBODY TESTING TOTALS BY QUARTER



HEA/PDS
3/87

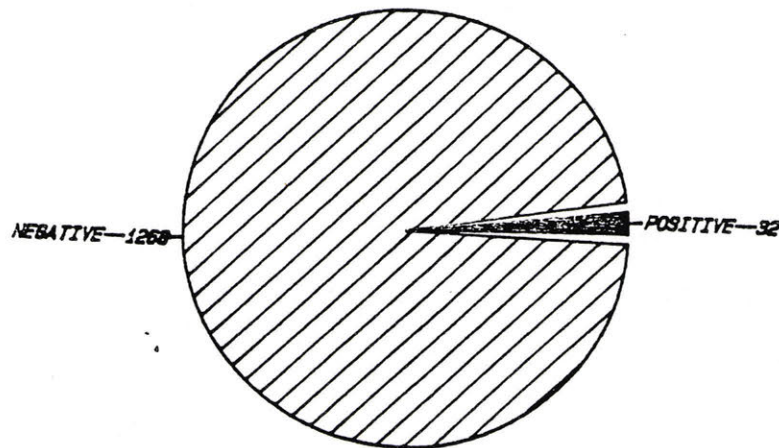
ALTERNATIVE TEST SITE SUMMARY STATISTICS
 PERSONS TESTED THROUGH 1/31/87
 TEST RESULTS BY MAJOR RISK GROUP



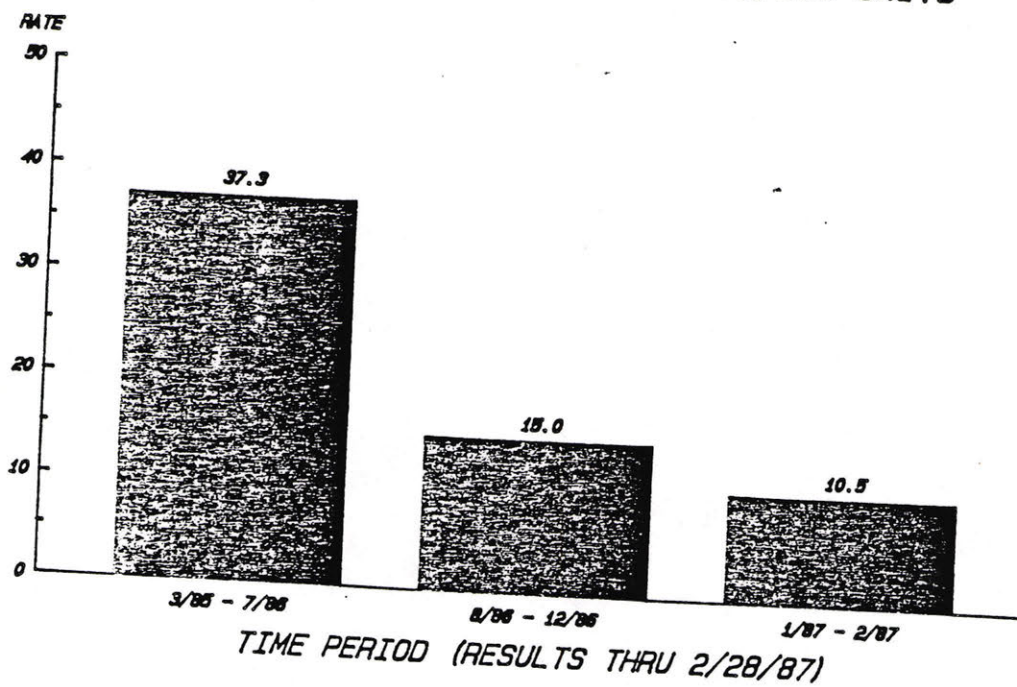
HEA/PDS
3/87

COUNTY OF ORANGE - AIDS MONITORING STATISTICS

JAIL TESTING PROGRAM



TEST RESULTS THRU 3/24/87

RED CROSS BLOOD SCREENING
HIV POSITIVITY RATE PER 100,000 UNITS

LOS ANGELES COUNTY
ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS)
MONTHLY SURVEILLANCE UPDATE
MARCH 31, 1987

NEW CASES THIS MONTH = 155

PRIMARY DISEASE*	CASES	PERCENT OF TOTAL	DEATHS	PERCENT DEAD
KS without PCP	641	22%	357	56%
PCP without KS	1591	54%	957	60%
Both KS and PCP	253	9%	167	66%
OI without KS or PCP	480	16%	326	68%
Total	2965	100%	1807	61%

*KS = Kaposi's sarcoma

PCP = Pneumocystis carinii pneumonia

OI = Other opportunistic infections

AGE	CASES	PERCENT OF TOTAL	RACE/ETHNICITY	CASES	PERCENT OF TOTAL
Under 5	16	1%	White	2082	70%
05 - 12	0	0%	Black	411	14%
13 - 19	6	0%	Hispanic	435	15%
20 - 29	534	18%	Asian	31	1%
30 - 39	1344	45%	Other/Unknown	6	0%
40 - 49	710	24%	Total	2965	100%
Over 49	355	12%			
Unknown	0	0%			
Total	2965	100%			

HISTORY OF INTRAVENOUS DRUG USE (adult cases)

SEXUAL ORIENTATION	Yes	No	Unk	Total	Percent IV Drug Users
Male-homosexual	199	1356	761	2316	9%
Male-bisexual	45	224	104	373	12%
Male-heterosexual	56	105	16	177	32%
Male-orientation unk	4	5	5	14	29%
Female-heterosexual	13	49	7	69	19%
Total	317	1739	893	2949	11%

PATIENT CHARACTERISTICS**

	MALES		FEMALES		TOTAL	
	CASES	% OF MALES	CASES	% OF FEMALES	CASES	% OF TOTAL
ADULT/ADOLESCENT:						
Homosexual or Bisexual	2700	94%	0	0%	2700	92%
Intravenous Drug User	61	2%	13	19%	74	3%
Hemophilia/Coag Disorder	16	1%	3	4%	19	1%
Heterosexual Contact***	8	0%	17	25%	25	1%
Transfusion	37	1%	20	29%	57	2%
None Apparent/Unknown	58	2%	16	23%	74	3%
Total	2880	100%	69	100%	2949	100%
PEDIATRIC:						
Hemophilia/Coag Disorder	0	0%	0	0%	0	0%
Parent at Risk	3	27%	5	100%	8	50%
Transfusion	8	73%	0	0%	8	50%
None Apparent/Unknown	0	0%	0	0%	0	0%
Total	11	100%	5	100%	16	100%

**Ordered hierarchically; cases with multiple characteristics are tabulated only in group listed first.

***With a person with AIDS or at risk for AIDS.

AIDS CASE-FATALITY BY HALF-YEAR OF DIAGNOSIS

Diagnosis date	Number of cases	Number of deaths	Case-fatality rate	Cumulative case-fatality rate
Prior to 1981	3	2	67%	67%
1981 Jan - June	8	8	100%	91%
July - Dec	12	8	67%	78%
1982 Jan - June	18	15	83%	80%
July - Dec	55	49	89%	85%
1983 Jan - June	109	94	86%	86%
July - Dec	146	121	83%	85%
1984 Jan - June	186	160	86%	85%
July - Dec	253	195	77%	83%
1985 Jan - June	382	298	78%	81%
July - Dec	451	299	66%	77%
1986 Jan - June	589	322	55%	71%
July - Dec	549	199	36%	61%
1987 Jan - Mar	204	37	18%	61%
TOTAL	2965	1807	61%	

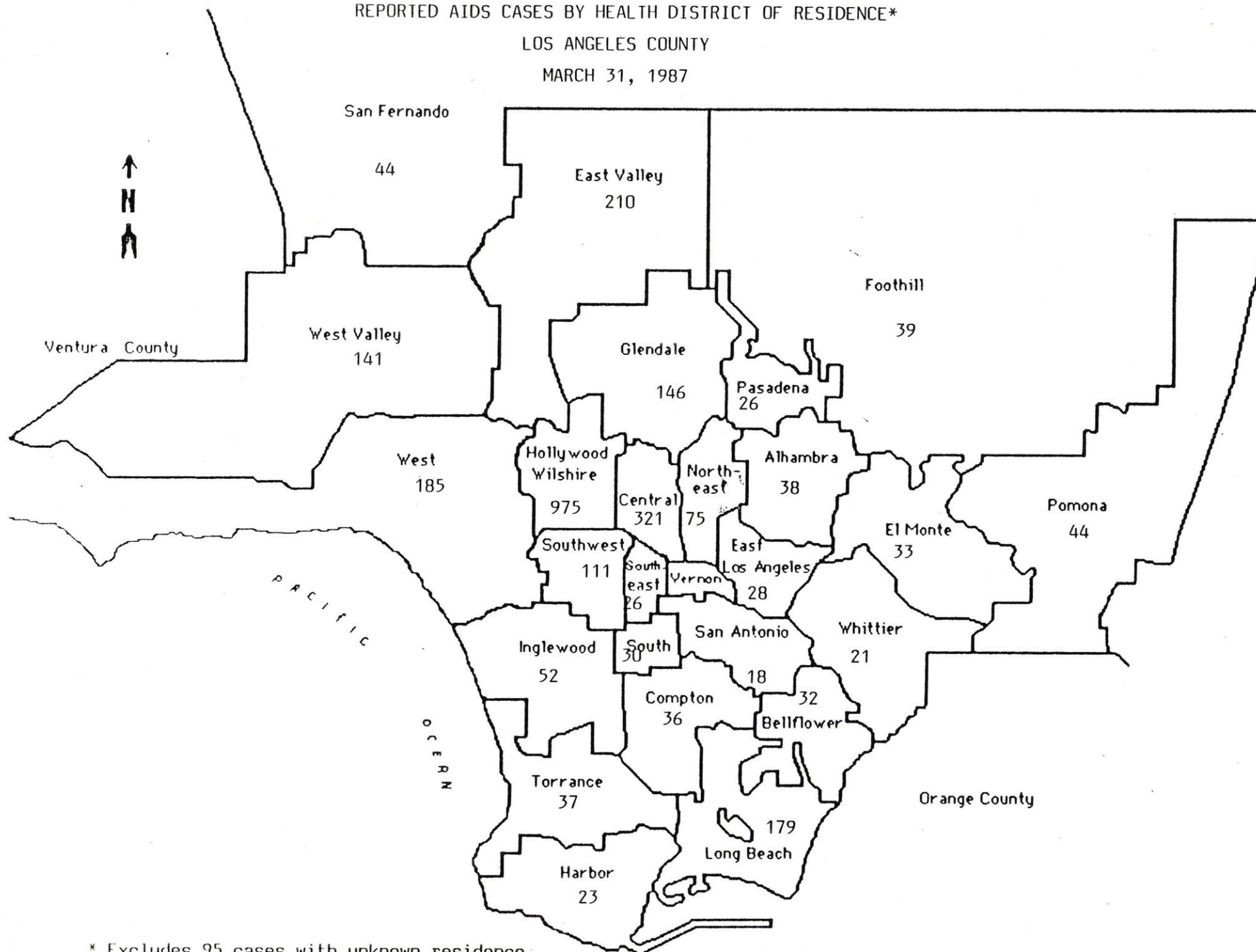
EPIDEMIOLOGIC PROFILE OF AIDS CASES IN LOS ANGELES COUNTY

Appendix III-c

Patient Characteristic	Number of cases	Mean age	Sex		Cauc	Race			Oth	Primary disease			
			M	F		Blk	Hisp			KS	Both	PCP	OI
			(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Homosexual or Bisexual	2700	37	100	0	73	12	14	1		23	9	52	15
Intravenous Drug User	74	34	82	18	32	35	32	0		7	3	62	28
Hemophiliac	19	38	84	16	63	16	16	5		0	5	68	26
Transfusion: Adult	57	56	65	35	61	9	19	11		3	2	72	23
Pediatric	8	38 mo	100	0	50	13	37	0		0	0	50	50
Heterosexual Contact	25	36	32	68	36	52	12	0		0	0	76	24
Pediatric: Parent at Risk	8	19 mo	38	63	0	50	50	0		0	0	38	62
Other/Unknown	74	41	78	22	36	36	24	3		7	0	70	23
Total	2965	38 *	98	2	70	14	15	1		22	9	54	16

*Adult cases only.

REPORTED AIDS CASES BY HEALTH DISTRICT OF RESIDENCE*
LOS ANGELES COUNTY
MARCH 31, 1987



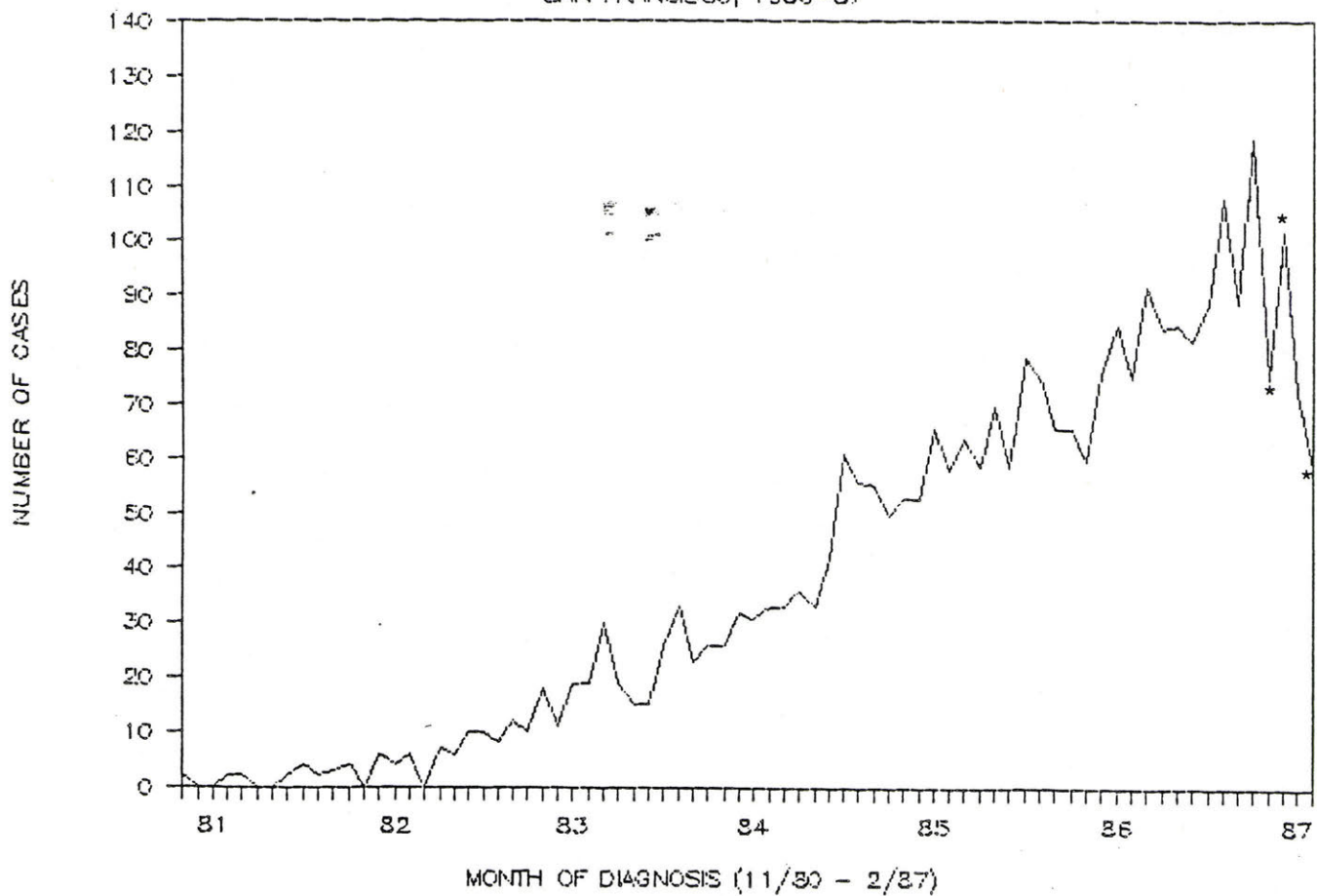
* Excludes 95 cases with unknown residence.

AIDS REPORTED CASES

(from 7/81 to) 2/28/87Total San Francisco Cases: 2,963Total San Francisco Deaths: 1,773Total S.F. cases month to date: 110Total S.F. deaths month to date: 67Total California cases: 6,917 cases; 3,512 deaths
(as of 1/31/87)Total U.S. cases: 31,036 cases; 17,851 deaths
(as of 2/23/87)

AIDS CASES BY MONTH OF DIAGNOSIS

SAN FRANCISCO, 1980-87



* Reporting for recent months is incomplete
AIDS Office

Acquired Immunodeficiency Syndrome (AIDS) Monthly Surveillance Report
Summary of Cases Meeting the CDC Surveillance Definition in San Francisco
Cases Reported through - 02/28/87

AIDS Cases by Transmission Category and Sex, San Francisco, 1981 - 1987(1)

Transmission Category(2)	SEX				Total	
	Male		Female		N	%
	N	%	N	%		
Adult/Adolescent						
Homosexual or bisexual male	2502	85.4	0	0.0	2502	84.7
Intravenous (IV) drug User	26	0.9	9	39.1	35	1.2
Homosexual/bisexual IV drug User	368	12.6	0	0.0	368	12.5
Hemophiliac/coagulation disorder	3	0.1	0	0.0	3	0.1
Transfusion recipient	14	0.5	7	30.4	21	0.7
Heterosexual contact(3)	7	0.2	7	30.4	14	0.5
None of the above/Other(4)	11	0.4	0	0.0	11	0.4
Subtotal: Adult/Adolescent	2931		23		2954	
Children (0-12 years)						
Transfusion recipient	3	60.0	1	25.0	4	44.4
Child of high risk/AIDS parent(5)	2	40.0	3	75.0	5	55.6
Subtotal: Children	5		4		9	
Total	2936		27		2963	

AIDS Cases by Age Group

AGE	Cases	%
0 - 4	7	0.2
5 - 12	2	0.1
13 - 19	5	0.2
20 - 29	422	14.2
30 - 39	1490	50.3
40 - 49	751	25.3
50 - 59	232	7.8
60 +	54	1.8
Total	2963	

AIDS Cases by Race or Ethnic Group

	Adult/Adolescent		Children (0-12 years)		Total	
	N	%	N	%	N	%
White	2552	86.4	4	44.4	2556	86.3
Black	166	5.6	3	33.3	169	5.7
Latino	193	6.5	2	22.2	195	6.6
Asian/Pac I.	41	1.4	0	0.0	41	1.4
Other	2	0.1	0	0.0	2	0.1
Total	2954		9		2963	

AIDS Deaths and Cases By Primary Disease Group

Primary Disease	Adult/Adolescent				Children (0-12 years)				Total			
	Deaths		Cases		Deaths		Cases		Deaths		Cases	
	N	%	N	%	N	%	N	%	N	%	N	%
KS without PCP	333	18.8	698	23.6	0	0.0	0	0.0	333	18.8	698	23.6
PCP without KS	936	52.9	1563	52.9	3	75.0	5	55.6	939	53.0	1568	52.9
Both KS and PCP	326	18.4	410	13.9	0	0.0	0	0.0	326	18.4	410	13.8
OI without KS or PCP	174	9.8	283	9.6	1	25.0	4	44.4	175	9.9	287	9.7
Total	1769		2954		4		9		1773		2963	

(1) Cases reported through 02/28/87.

(2) Cases with more than one risk factor (other than the combinations listed in the tables) are tabulated only in the most likely transmission category.

(3) Includes persons who have had heterosexual contact with a person with AIDS or at risk for AIDS and persons without other identified risks who were born in countries in which heterosexual transmission is believed to play a major role although precise means of transmission have not yet been fully defined.

(4) Includes patients on whom risk information is incomplete (due to death, refusal to be interviewed or loss to follow-up), patients still under investigation, men reported only to have had heterosexual contact with a prostitute, and interviewed patients for whom no specific risk was identified.

(5) Epidemiologic data suggest transmission from an infected mother to her fetus or infant during the perinatal period.

Appendix IV-c

Acquired Immunodeficiency Syndrome (AIDS) Monthly Surveillance Report
Summary of Cases Meeting the CDC Surveillance Definition in San Francisco
Cases Reported through - 02/28/87

AIDS Cases by Transmission Category and Year of Diagnosis, San Francisco, 1981 - 1987(1)

Transmission Category(2)	Year of Diagnosis													
	1981		1982		1983		1984		1985		1986		1987	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Adult/Adolescent														
Homosexual or bisexual male	23	85.2	97	95.1	241	85.2	447	83.4	674	84.5	903	83.2	117	88.6
Intravenous (IV) drug User	0	0.0	0	0.0	2	0.7	4	0.7	8	1.0	20	1.8	1	0.8
Homosexual/bisexual IV drug User	2	7.4	3	2.9	36	12.7	82	15.3	98	12.3	138	12.7	9	6.8
Hemophilia/coagulation disorder	0	0.0	0	0.0	0	0.0	0	0.0	2	0.3	1	0.1	0	0.0
Transfusion recipient	0	0.0	0	0.0	0	0.0	0	0.0	11	1.4	10	0.9	0	0.0
Heterosexual contact(3)	0	0.0	0	0.0	3	1.1	2	0.4	1	0.1	7	0.6	1	0.8
None of the above/Other(4)	1	3.7	0	0.0	0	0.0	1	0.2	3	0.4	4	0.4	2	1.5
Children (0-12 years)														
Transfusion recipient	0	0.0	0	0.0	1	0.4	0	0.0	1	0.1	1	0.1	1	0.8
Child of high risk/AIDS parent(5)	1	3.7	2	2.0	0	0.0	0	0.0	0	0.0	1	0.1	1	0.8
Total	27		102		293		536		798		1085		132	

AIDS Cases by Race/Ethnic Group and Transmission Category, San Francisco, 1981 - 1987(1)

Transmission Category(2)	Race/Ethnicity									
	White		Black		Latino		Asian/Pac I.		Other	
	N	%	N	%	N	%	N	%	N	%
Adult/Adolescent										
Homosexual or bisexual male	2182	85.4	113	66.9	170	87.2	35	85.4	2	100.0
Intravenous (IV) drug User	11	0.4	15	8.9	7	3.6	2	4.9	0	0.0
Homosexual/bisexual IV drug User	332	13.0	24	14.2	10	5.1	2	4.9	0	0.0
Hemophilia/coagulation disorder	2	0.1	0	0.0	1	0.5	0	0.0	0	0.0
Transfusion recipient	15	0.6	3	1.8	1	0.5	2	4.9	0	0.0
Heterosexual contact(3)	6	0.2	7	4.1	1	0.5	0	0.0	0	0.0
None of the above/Other(4)	4	0.2	4	2.4	3	1.5	0	0.0	0	0.0
Children (0-12 years)										
Transfusion recipient	4	0.2	0	0.0	0	0.0	0	0.0	0	0.0
Child of high risk/AIDS parent(5)	0	0.0	3	1.8	2	1.0	0	0.0	0	0.0
Total	2556		169		195		41		2	

- (1) Cases reported through 02/28/87.
- (2) Cases with more than one risk factor (other than the combinations listed in the tables) are tabulated only in the most likely transmission category.
- (3) Includes persons who have had heterosexual contact with a person with AIDS or at risk for AIDS and persons without other identified risks who were born in countries in which heterosexual transmission is believed to play a major role although precise means of transmission have not yet been fully defined.
- (4) Includes patients on whom risk information is incomplete (due to death, refusal to be interviewed or loss to follow-up), patients still under investigation, men reported only to have had heterosexual contact with a prostitute, and interviewed patients for whom no specific risk was identified.
- (5) Epidemiologic data suggest transmission from an infected mother to her fetus or infant during the perinatal period.

Appendix IV-d

Acquired Immunodeficiency Syndrome (AIDS) Monthly Surveillance Report
Summary of Cases Meeting the CDC Surveillance Definition in San Francisco
Cases Reported through - 02/28/87

Aids cases by year of diagnosis and race. (1) (2)

Race/ Ethnic	Year of Diagnosis													
	1981		1982		1983		1984		1985		1986		1987	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
White	23	85.2	87	85.3	257	30.3	475	88.6	630	65.2	919	34.7	115	87.1
Black	2	7.4	6	5.9	15	5.7	23	4.3	45	5.6	72	6.6	5	3.3
Latino	2	7.4	8	7.3	9	3.2	34	5.3	53	7.4	74	6.3	9	5.3
Asian/Pac I.	0	0.0	1	1.0	1	0.4	4	0.7	14	1.3	13	1.7	3	2.3
Other	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	2	0.2	0	0.0
Total	27		102		293		536		738		1085		132	

AIDS Cases by Race/Ethnic Group, Sex, and Age Group, San Francisco, 1981 - 1987(1)

AGE	Race/Ethnicity									
	White		Black		Latino		Asian/Pac I.		Other	
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
0 - 4	2	0	0	3	2	0	0	0	0	0
5 - 12	1	1	0	0	0	0	0	0	0	0
13 - 19	2	0	1	0	2	0	0	0	0	0
20 - 29	351	1	32	1	33	0	4	0	0	0
30 - 39	1283	5	77	1	100	0	23	0	1	0
40 - 49	659	1	39	1	39	1	9	2	1	0
50 - 59	202	3	8	3	14	0	2	0	0	0
60 +	42	4	3	0	4	0	1	0	0	0
Total	2541	15	160	9	194	1	39	2	2	0

(1) Cases reported through 02/28/87.

(2) This table cumulates cases by DATE OF DIAGNOSIS rather than DATE OF REPORT. Because of this difference, totals may differ from those in other tables and will change with late reports and new data or information.

Appendix IV-e

Acquired Immunodeficiency Syndrome (AIDS) Monthly Surveillance Report
Summary of Cases Meeting the CDC Surveillance Definition in San Francisco
Cases Reported through - 02/28/87

AIDS Cases by primary diagnosis, San Francisco, 1981 - 1987(1)

Primary Diagnosis	N	Percent
Pneumocystis carinii pneumonia	1718	58.0
Kaposi's sarcoma	896	30.2
Disseminated cryptococcal infection	92	3.1
Candida esophagitis	43	1.5
Non-Hodgkins lymphoma	43	1.5
Atypical mycobacterial infection	40	1.3
Cryptosporidiosis	39	1.3
Cytomegalovirus infection	36	1.2
Toxoplasmosis	18	0.6
Primary lymphoma of the brain	14	0.5
Progressive multifocal leukoencephalopathy	11	0.4
Disseminated herpes simplex virus infection	8	0.3
Histoplasmosis	2	0.1
Isosporiasis	2	0.1
Lymphoid interstitial pneumonia	1	0.0
Total	2963	100.0

AIDS Cases and Case-Fatality rates by half year of diagnosis

	Number of Cases	Number of known deaths	Case-Fatality Rate
1981 Jan - June	8	6	75.0
July - Dec	19	18	94.7
1982 Jan - June	33	29	87.9
July - Dec	69	62	89.9
1983 Jan - June	117	95	81.2
July - Dec	166	151	91.0
1984 Jan - June	208	179	86.1
July - Dec	328	279	85.1
1985 Jan - June	376	298	79.3
July - Dec	422	271	64.2
1986 Jan - June	503	237	47.1
July - Dec	582	139	23.9
1987 Jan - June(1)	132	9	6.8
Total	2963	1773	59.8

(1) Cases reported through 02/28/87.

(2) This table cumulates cases by DATE OF DIAGNOSIS rather than DATE OF REPORT. Because of this difference, totals may differ from those in other tables and will change with late reports and new data or information.

Acquired Immunodeficiency Syndrome (AIDS) Monthly Surveillance Report
Summary of Cases Meeting the CDC Surveillance Definition in San Francisco
Cases Reported through - 02/28/87

AIDS Cases by year and month of Primary Diagnosis, San Francisco, 1981 - 1987(1)

DIAGNOSED (2)	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC
1981	0	2	2	0	0	2	4	2	3	4	2	6
1982	4	6	0	7	6	10	10	8	12	10	18	11
1983	19	19	30	19	15	15	26	33	23	26	26	32
1984	31	33	33	36	33	42	61	56	55	50	53	53
1985	66	58	64	59	70	59	79	75	66	66	60	76
1986	85	75	92	84	85	82	89	108	89	119	75	102
1987	73	59	0	0	0	0	0	0	0	0	0	0

AIDS Cases by year and month of Report to SFDPH, San Francisco, 1981 - 1987(1)

REPORTED	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC
1981	0	0	0	0	0	0	7	5	3	3	0	6
1982	3	8	0	5	6	9	6	11	8	8	18	12
1983	15	12	31	17	19	16	14	28	22	24	22	29
1984	31	39	33	38	36	33	55	50	38	58	49	42
1985	62	61	69	64	67	53	64	67	62	60	69	63
1986	64	101	74	90	83	108	100	98	78	119	108	107
1987	93	110	0	0	0	0	0	0	0	0	0	0

AIDS Cases by year and month of Death, San Francisco, 1981 - 1987(1)

DEATH (3)	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC
1981	0	0	0	0	0	0	2	0	1	1	1	2
1982	1	3	1	2	2	0	5	5	1	2	4	5
1983	4	6	10	6	4	10	6	15	16	12	20	11
1984	20	16	16	21	21	22	23	24	26	26	30	39
1985	36	35	34	37	37	52	42	34	49	47	40	56
1986	47	58	44	62	76	53	51	58	62	61	69	82
1987	66	43	0	0	0	0	0	0	0	0	0	0

(1) Cases reported through 02/28/87.

(2) This table cumulates cases by DATE OF DIAGNOSIS rather than DATE OF REPORT. Because of this difference, totals may differ from those in other tables and will change with late reports and new data or information.

(3) This table cumulates cases by DATE OF DEATH rather than DATE OF REPORT. Because of this difference, totals may differ from those in other tables and will change with late reports and new data or information.

DEPARTMENT OF HEALTH SERVICES

2151 BERKELEY WAY
BERKELEY, CA 94704

CALIFORNIA MORBIDITY SUPPLEMENT #20, May 24, 1985

HTLV III ANTIBODY TESTING AND CONFIDENTIALITY

On March 2, 1985 the U.S. Food and Drug Administration licensed for use an enzyme-linked immunosorbent assay (ELISA) for the detection of antibodies to the human T-cell lymphotropic virus III (HTLV III), the probable causative agent of the acquired immune deficiency syndrome (AIDS). Primary use of the ELISA HTLV III antibody test to date has been to screen blood donors to minimize the risk of HTLV III infection by blood transfusion. In California, blood bank screening of donors for HTLV III antibody is mandated by law (June 3, 1985) as is the soon to be initiated alternative test site program for persons in AIDS risk groups who want free and immediate HTLV III antibody tests. Licensed clinical laboratories, utilized by physicians throughout the State, may also provide HTLV III antibody testing services.

The newly enacted laws created by Assembly Bills 403 and 488 (California Morbidity #13 April 5, 1985) require confidentiality of HTLV III antibody test results and protect the privacy of individuals who are the subjects of such tests. The Department of Health Services has summarized its interpretation of these requirements as follows:

1) Physicians who want to test patients for HTLV III antibody must obtain specific consent from the patient in the form of a written statement signed by the patient affirming that consent was obtained. For donors tested for antibody at blood banks, this requirement is met when donors sign the mandated written statement confirming that they have been notified in writing of the conditions of donation as set forth in section 1603.3(a)(1-6) of the Health and Safety Code (e.g., donors confirmed to be positive for HTLV III antibodies will be placed on a confidential statewide Deferred Donor Register without mention of the reason for being included on the register). The requirement of written consent does not apply to tests performed at alternative sites where a coded system will be used that does not link individual identity with tests requests or results.

2) Physicians who wish to disclose HTLV III antibody test results obtained in a patient under their care and treatment to a third party must obtain written authorization from that patient for each separate disclosure of the results and specify to whom the disclosure will be made. "Disclosed" as used in the law means to disclose, release, transfer, disseminate or otherwise communicate all or any part of any record orally, in writing, or by electronic means to any person or entity.

The new law further provides that no person can be compelled to identify or provide identifying characteristics which would identify any individual who is the subject of a blood test to detect antibodies to HTLV III in any proceeding (including civil, criminal, administrative, or legislative proceedings) unless written authorization has been given by the test subject for that purpose.

Persons who negligently or willfully disclose results of HTLV III antibody tests to any third party in a way which identifies or provides identifying characteristics of the person to whom the test results apply (except pursuant to a written authorization or in accordance with any reporting requirement for a diagnosed case of AIDS or reports required by blood banks and plasma centers in accordance with AB 488) are subject to various civil or criminal penalties as specified in section 199.21 of the Health and Safety Code.

The Infectious Disease Section has been asked if clinical laboratories must also obtain separate prior written consent from a test subject before performing the HTLV III antibody test. We have interpreted the law to require that only the person (physician) who ordered the HTLV III antibody test needs to obtain the written consent. The laboratory would appear to be only acting as the agent of the physician who ordered the test. This interpretation is based upon discussions with legislative staff who drafted AB 403. The laboratory, however, has responsibility (as with all other tests) for maintaining the confidentiality of test result records.

While all laboratory test results are considered sensitive and confidential, several procedures have been suggested to minimize the possibility of any break in confidentiality.

1) Blood specimens and laboratory forms can be submitted to the laboratory in coded form so that identifying information about the test subject is not available to link the specimen or laboratory report with the identity of the test subject.

2) A separate laboratory form may be used for submitting or reporting the results of HTLV III antibody tests to facilitate management of these sensitive data.

3) When the written consent for performing the antibody test is obtained, consideration should be given to including on the consent form information as to how the test results and identifying data might be handled. For example, will the specimen and laboratory slip be coded? If not coded, what classifications of medical personnel (or others) might see the report of test results as a matter of routine record processing? Will the test results form be part of the patient's hospital or office chart, etc.?

All health care providers should be aware of the provisions of AB 403 and 488 and take appropriate measures to safeguard the confidentiality of HTLV III antibody test requests and results.

The Department has provided this general summary of these selected new statutory requirements to facilitate prompt and consistent conformity with the requirements. Individual hospitals, physicians, laboratories, etc., are encouraged to consult their attorneys regarding how to best comply with the law based upon their particular concerns and circumstances.

CASE MANAGEMENT OF AIDS PATIENTS

Presented by

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I. RATIONALE

The AIDS epidemic will have an extraordinary impact on national health care expenditures in the coming years. The Public Health Service has projected that some 174,000 AIDS patients will be alive at some time during 1991. The costs of providing health care for these individuals have been estimated to range from eight billion to sixteen billion dollars. The majority (80%) of these expenditures will occur outside of San Francisco and New York City. Nonetheless, San Francisco anticipates that AIDS cases will use 9.5% of available hospital beds in 1991, a level nearly five times the current rate of use. Given the magnitude of the impact of the AIDS epidemic on the nation's health care system and health care finances, it is incumbent upon all public health officials and health care providers to develop and implement the most humane, effective, and cost conscious systems for providing health care to AIDS victims. Resources, both human and financial, cannot keep pace with this epidemic. All resources must be fully coordinated for maximum coverage of the population needs.

Case management allows for not only cost effective care but also more humane care based on individual assessments of the patient's needs. The individual AIDS patient would depend upon a variety of community resources during his illness. Haphazard and unplanned use of these resources is not only ineffective but inhumane. Each patient deserves the dignity of having an advocate for his needs in a system which by definition will involve interfacing with many different types of providers and different agencies. The case manager can most appropriately serve in this role.

II. NEEDS STATEMENT

There is no typical AIDS patient. This statement will be particularly true in coming years as the epidemic spreads into population groups previously relatively unaffected. San Francisco has developed highly regarded community-based care and case management systems for the provision of humane and economic care to AIDS patients. The San Francisco experience has been primarily with the gay population, however, and its success can be partially attributed to an extraordinary support system and network of organizations in the gay community devoted to the effort. As the epidemic spreads into the I.V. drug using and other heterosexual groups, comparable types of support systems and community organizations will not likely be readily available. This will be particularly true among the I.V. drug using population. New and innovative approaches to case managed care will have to be developed to reach this population. Pediatric AIDS cases are expected to increase almost tenfold to approximately 3,000 cumulative cases by the end of 1991. The pediatric population also presents special problems for case managed care.

There is, at the present time, a dearth of long-term care beds available to AIDS patients. This is partly a financial issue and partly an educational issue. Both issues need to be addressed aggressively to create the availability of long-term care beds for AIDS patients. Such extraordinary efforts as the reactivation of the public health hospital in San Francisco to serve as a long-term care facility for AIDS patients need also to be explored.

Case management should also address the special needs of people of color who have AIDS or ARC. We must develop care facilities which are accessible to people of color both culturally and linguistically, volunteer networks and special

support systems for families. This system would recognize the different culture reactions to the disease.

III. STRATEGIES

The spectrum of care required for AIDS patients represents a spectrum of HIV-related symptoms in the affected population. Asymptomatic HIV-positive individuals may require only appropriate counselling and psychological support. ARC patients will require ongoing monitoring and treatment of symptoms, as well as psychological support. Full blown AIDS cases will require medical intervention ranging from monitoring and support during quiescent phases of the illness to aggressive, intensive intervention for secondary infections and administration of chemotherapy such as AZT. Until now, without effective medications, it has been assumed that most patients will be dead within two years after diagnosis. With the advent of AZT and the expectation that there will be more drugs which delay the course of the disease, we must begin to consider AIDS as a chronic disease. This means different strategies and long term planning for the care of patients infected with HIV. As patients live longer with fewer life-threatening crises, they will require more and different types of care. In addition, there is a spectre of a large number of patients with neurological manifestations only. As the predictions of many cases of chronic dementia are borne out, there will be a significant impact on mental health facilities as well as skilled nursing facilities. In the terminal stages of the disease, appropriate hospice care should be made available to those desiring it.

This wide spectrum of disease manifestations will occur in patients receiving care in a wide spectrum of health care systems. Much care is currently being rendered in the private sector for insured individuals. The role of the public

sector will increase as the epidemic spreads into uninsured populations. Public institutions and systems will then be impacted even more heavily than at the present time. Part of this distribution of care will depend upon the availability of Medi-Cal and Medicare coverage for AIDS patients and the willingness of the private medical community to accept these patients. (ARC should be included as presumptive disability for Medi-Cal eligibility or there will be further disproportionate impact on the public system in the form of MIA expenses).

A variety of case management systems can be developed in public settings, private settings, and combinations of the two. It is important for public health leadership in each county to assure that appropriate case managed systems are available to all AIDS patients. Case management systems should consist of the following elements:

1. An identified Case Manager. The case management role may be performed by a variety of types of providers. In many cases the primary care physician is the most appropriate person. In other cases a public health nurse, social worker, family nurse practitioner, psychologist, or other health care professional may more appropriately fill the role. The role is primarily one of patient advocacy and coordination of available services to meet the individual needs of the AIDS patient. This requires not only being aware of all of the community resources available to provide services for the AIDS patient, but also having the time, capability and interest to access and coordinate those services. Ideally the Case Manager will provide a continuity of care for the patient from the early recognition to the terminal stages of the illness. Thus the case manager will interface with the patient in a variety of settings dependent upon the particular stage of illness of the disease as well as the professional role of the case manager.

The case manager is responsible for the overall management of the care provided to a person infected with HIV. He integrates all services and insures continuity of care. One vehicle for insuring continuity of care is an Interdisciplinary Team Approach which will be utilized whenever appropriate, with the case manager heading the team and responsible for the implementation of its decisions.

Case management has two focus areas: the individualized care plan and client advocacy. In developing and implementing an individualized care plan, the case manager: (1) develops a written individualized care plan for each client and enters it into the case management record; (2) implements and coordinates all aspects of the plan; (3) performs an initial medical and social history on each client; (4) explains to the client the care plan recommendations, including the provisions and explanations, special instructions, transportation and housing arrangements; (5) reviews the care plan with the client and provides the client with ongoing information; (6) receives advice and input from the patient on the plan and any subsequent changes and modifies the plan based on this input; (7) assists the patient in fulfilling the plan's recommendations (i.e. referrals, tests, special appointments, etc.); (8) maintains ongoing contact with all providers of care, especially the physician and home care providers and modifies plan based on this input; (9) modifies the plan as problems are ameliorated or resolved or as new problems arise; (10) assures compliance with all the recommendations in the plan with results and progress recorded in the case management record; (11) assures the completion and accuracy of the documentation in the case

management record; (12) uses all available methods to assure continuity of care including cooperative care conferences, special case presentations, etc.; (13) evaluates the care plan and the specific services which the client is receiving by assessing the patient's health and the appropriateness of the intervention that is being evaluated.

In his client advocacy role, the case manager (1) maintains communication and close contact with the client throughout his care; (2) advocates for the needs of the client with inpatient and outpatient medical services as well as all service providers affecting the client; (3) keeps track of patient attendance and appointments, identifying the reason for missing appointments, etc.; (4) assist the patient in problem solving, making herself/himself available to the patient; (5) assures that the patient's own decision-making abilities are utilized to the maximum.

2. Primary Care Physician. In some systems there will be a large enough volume of AIDS patients to warrant specialized AIDS clinics. In other systems, the majority of outpatient care will be delivered in primary care settings, hopefully by physicians who are not only familiar with AIDS treatment issues, but are also able to access specialty consultation and an AIDS resource support team as needed.
3. Specialty Consultation. Much of the expertise in treating AIDS patients to date has been concentrated in a few large public hospital settings. Methods for spreading that expertise out to other public and private providers in the community must be developed. This could be done through continuing education as well as consultation networks.

4. Public Health Nurses. Public Health Nurses, visiting Nurses or Home Health Nurses will be the primary coordinators of in-home care. They will be providing services ranging from routine followup visits to coordination of full-scale, in-home care provided by home health aides occupational therapists, physical therapists and volunteers. There will also be a need for home I.V. infusion programs with personnel trained to support this program.
5. Social Workers. AIDS patients will require a great deal of social worker support for issues including housing and living arrangements, health insurance and welfare issues, and counseling.
6. Psychologists. Psychologists and other mental health professionals can provide specialized types of counseling necessary for AIDS patients. These will be much the same issues confronting other types of terminally ill patients, but with obvious AIDS-related issues. There is also going to be a need for less traditional kinds of mental health therapy including trained peer counselors (volunteers) and support groups for various needs (i.e., AIDS patients, family, friends, lover, HIV positive patients and worried well). Patients with chronic dementia and other organic mental health disorders will need appropriate psychiatric treatment.
7. Legal Services. AIDS patients may face a variety of legal problems ranging from employment discrimination to housing discrimination. Legal services may be required to assure that legislated protections are available for individual patients. The legal issues of terminal illness will also need to be dealt with. Patients with dementia will need conservatorship and guardianship services.

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8. Volunteers (Hospice Programs and AIDS Support Programs). Volunteers who have been trained to deal with AIDS issues as well as terminal illness issues are essential to the success of any case management. There will never be enough professional employed personnel available to meet the needs of the anticipated number of AIDS patients. The success of case management systems to date has been largely due to the participation of volunteers from community organizations. It is essential to continue to tap this source of support. Volunteers can be coordinated through AIDS task forces or hospice programs, recognizing the cross-training of individuals from either organization is essential. Volunteers should be conversant, not only in the specifics of dealing with AIDS, but also should have appropriate training in dealing with terminal illness and psychological aspects of death and dying. Ideally, community-based and publicly-sponsored hospice programs and AIDS task forces can work together to maximally benefit the AIDS patient. These efforts must also be integrated with those of the County Home Health Agency and all other support services. Those counties, such as Contra Costa, with all three programs (Hospice, AIDS support programs and Home Health Agencies) available under the authority of one department are in a unique position to coordinate services appropriately. Other counties may wish to consider developing their own in-house Home Health Agencies as demand increases.

Such a public case management system can form the focal point for coordination of community service organizations, as well as interfacing with private providers. This system requires expertise in training, excellent communication and good will.

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It is also important to involve the AIDS patients themselves, not only in their own self care, but also in participation and support programs for other AIDS patients. The San Francisco experience has proven the value of utilizing the support of AIDS patients for each other.

9. Acute Care Hospitals. Inpatient care for the AIDS patient will occur in a variety of inpatient settings ranging from the small community hospital to the large county or university hospital. With an appropriate volume of patients, specialized AIDS wards can be established with the advantages inherent in having a staff committed to the program and well versed in AIDS issues. Nevertheless, appropriate and humane care can be delivered on the wards of any general hospital with the appropriate staff training and support. This training and support must be made available also to hospitals in smaller communities. A case management system should follow the patient into the acute care setting to ascertain coordination with outpatient services.
10. Long Term Care. Perhaps the most difficult issue facing those responsible for providing care for AIDS patients is the profound lack of long term care facilities. This is a crisis situation in many counties. The case management system should deal with this issue as well by advocating for the availability of long term care facilities and placing patients appropriately. Alternatives to long term care can also be sought. San Francisco again provides a model for community-based living arrangements. Non-institutional care seems to be the most significant aspect of cost reduction. It also may be the most psychologically healthy for the patient. There is however, the harrowing projection of neurologically impaired AIDS patients requiring the care provided in skilled nursing facilities.

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There is no single model for a case management system which will apply to all settings and counties. The list of the above elements may differ from setting to setting. Important, however, is the concept and principle of a system to assure coordinated care and access to all available community resources for all AIDS patients. We recommend this as the guiding principle for the delivery of health care to AIDS patients.

A number of reimbursement issues will have to be faced in developing case management systems. Many third party payors including Medi-Cal and Medicare do not always pay appropriately for in-home care, and specifically for hospice care. We must advocate for the inclusion of these services in benefit packages and adequate reimbursement for their provision. Moreover, most third party payors do not reimburse for the specific case management service that we have been describing. We must encourage appropriate recognition and reimbursement of this role in the health care system. Without appropriate funding, any case management system will remain a paper plan.

The emphasis of case managed care is for the patient to be treated in the community and not in institutions. Moreover, the focus of this approach is to normalize life with the disease and including an emphasis on life activities which go on despite the disease.

IV. EVALUATION

It is obvious that provision of health care in a coordinated fashion maximizing community resources is a laudable goal for the provision of humane and effective care. It is also assumed that care delivered in such a fashion will also be more economical. This assumption stems partly from the San Francisco experience

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where inpatient lengths of stay and total costs have been significantly less than that for AIDS patients treated in other systems. It remains to be proven whether Case Management Systems can accomplish similar savings in other settings with different groups of patients. We therefore recommend that efforts to promote Case Management Systems be accompanied by requirements for evaluation and monitoring of those systems to document their efficacy in terms of outcome and economic savings. A data base must be developed to obtain demographic data, medical parameters, and identifiable outcome data (length of stay, quality of life, etc.). Only then can we begin to make informed decisions with regard to where to spend the scarce health care dollars to combat this devastating disease.