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Ron
12/5/85

American College Health Association
Task Force on the Acquired Immunodeficiency Syndrome (AIDS)
Statement on HTLV-III Antibody Testing
December, 1985

The American College Health Association recognizes that there are important limitations to the clinical application of the currently available enzyme-linked immunosorbent assay (ELISA) test for antibodies to human T-lymphotropic virus, type III (HTLV-III), the agent thought to cause the Acquired Immunodeficiency Syndrome (AIDS). These include:

1. The occurrence of false positive tests in a small but significant percentage of people whose blood does not in fact contain antibodies to HTLV-III and who are not infected with the organism. Some of these people have cross-reacting antibodies; in other circumstances, technical problems cause the test to be falsely positive. These people have negative confirmatory tests done by the western blot method. Some technical problems are specific to individual test kits and procedures. *percentage?*

2. The rare presence of false negative tests in some people who actually have been infected by HTLV-III, and whose blood does in fact contain antibody. *%?*

3. The occurrence of negative tests in people who are in fact infected, but whose antibody response has not yet occurred; this situation is encountered in the first 6-8 weeks after infection. *%?*

4. The occasional existence of negative tests in some people who are infected with HTLV-III and may even have symptomatic immune deficiency and recoverable virus in blood and body fluids. *%?*

5. The need for confirmation of positive results by a more specific procedure, the western blot test. *only in low risk groups, if ELISA done 2X and is indeterminate*

6. The absence of any specific clinical correlates to a positive test result. People with confirmed positive tests may have:

a. Asymptomatic infection, currently marked only by a positive antibody test. Most of these people are contagious (infectious); some are not. Some may progress to have AIDS-related complex (ARC) or AIDS itself, and others will stay

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a. Asymptomatic infection, currently marked only by a positive antibody test. Most of these people are contagious (infectious); some are not. Some may progress to have AIDS-related complex (ARC) or AIDS itself, and others will stay

healthy for years. No feature of the ELISA or Western Blot test distinguishes among these possibilities.

b. Thrombocytopenia (low platelet count) with or without evidence of a hemostatic defect (tendency to bruise or bleed easily). Some of these people will progress to develop ARC or AIDS; others will stay clinically stable for long periods of time.

c. AIDS-Related Complex (ARC). Some of these people will progress to have AIDS itself; some will regress to an asymptomatic state. Many appear to remain clinically stable for long periods. Again, no feature of the ELISA or Western Blot test distinguishes among these possible outcomes.

d. Full-Blown AIDS manifest by major opportunistic infection; premature, unusual cancers, or both.

7. The tendency of many people to misinterpret the test and misunderstand its results. A positive test result is commonly misapprehended as evidence of the existence of AIDS itself or of the inevitability of development of AIDS. In some contexts, a positive test has been interpreted as evidence of homosexuality or drug abuse. Positive test results, whether or not they are confirmed, have been regarded as reason for termination of employment, refusal of insurance coverage, and exclusion from school.

8. The fact that the ELISA test, when applied as a screening device to a population in which the prevalence of HTLV-III infection is low, becomes significantly less reliable in correctly identifying seropositive people (those with HTLV-III antibodies). Such populations include, for example, unselected entering college and university students, health sciences students, and institutional employees.

9. The fact that the advice, counsel, and instructions given to people in high risk groups for AIDS are similar, whether or not testing is done; that is, that a positive test does not materially change the counsel provided, though it may certainly confirm suspicious and elevate anxiety. Whether or not they are tested, people in high risk groups must not engage in any activities which could transmit AIDS.

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The American College Health Association further recognizes that the tests for antibody to HTLV-III were developed as procedures to screen donated blood, and it wholeheartedly supports their utilization for that purpose. ACHA encourages all citizens to abide by the request of the American Red Cross and

the Public Health Service that persons in certain defined high risk groups voluntarily exclude themselves as blood donors. Those groups include:

1. Anyone who demonstrates the signs or symptoms of AIDS.
2. Males who have had sex with more than one male since 1978.
3. Males whose male sexual partner has had sex with more than one male since 1978.
4. Past or present abusers of intravenous drugs.
5. Hemophiliacs.
6. Sexual partners (male and female) of persons in these groups.

Under no circumstances should individuals use blood donation as a way to be tested for HTLV-III antibodies, however. The occurrence of even a small percentage of false negative tests and the existence of infectious virus in people who have been quite recently infected and still have no serum antibody demand that individuals in risk groups not even attempt to give blood.

Despite the limitations of the tests, they may provide important, useful information in certain circumstances. Given the likelihood that people with positive tests are infectious, a positive test may provide greater motivation for alterations in behavior than the simple possibility or probability of infection as assessed by a patient and his/her health care provider. In certain clinical circumstances, the test is an important adjunct to the evaluation of an illness, especially when the symptoms and signs may suggest AIDS or an AIDS-related disorder. Some people are so worried about possible exposure to HTLV-III that the concern itself becomes a distraction, a stressor, and a limitation to their function; assuming that the potential exposure occurred at least 2-3 months prior to the intended time of testing, the test may relieve anxiety, if negative, or bring more useful counseling approaches if confirmed positive. Those involved in a new relationship may desire testing to protect the health of both partners; in certain circumstances, the test, performed on both partners, may be helpful. Women in high risk groups who are or intend to become pregnant may wish testing in order to avoid perinatal transmission to offspring.

In most jurisdictions, only cases of AIDS meeting the criteria of the revised surveillance definition of the Centers for Disease Control (see MMWR 1985; 34:373-375) are reportable

to local health authorities. There are, however, some (Colorado) in which the fact of a positive HTLV-III antibody test, with or without evidence of ARC or AIDS must be reported. In some areas, such reports must include information about the sexual preference of the person whose results are reported.

Even where test results are not reportable by law, they commonly become part of the medical record to the person tested. Such information is protected from disclosure without consent of the tested individual by a number of statutes, and thus is "confidential." However, access to the information may be secured by potential employers, insurers, and others who produce an authorization signed by the person tested. The results then become open to the interpretation of the agency or individual securing consent for their release.

Truly anonymous testing is available in certain areas. In these testing programs, no disclosure of the name of the individual tested needs be made, and no named record is generated. Thus, no untoward consequences of accidental or malicious compromise of confidential data can occur.

USING THESE FACTS AND OBSERVATIONS, THE AMERICAN COLLEGE HEALTH ASSOCIATION MAKES THE FOLLOWING RECOMMENDATIONS IN REGARD TO TESTING FOR ANTIBODY TO HTLV-III:

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1. The American College Health Association recommends that any individual so requesting be provided accurate, timely information on which he or she can base a rational, personal decision about taking the HTLV-III antibody test. The issues involved in such decisions are too complex and personal to allow for blanket recommendations that any group should or should not be tested.

yes
2. Those who counsel or advise students or employees about HTLV-III antibody testing must themselves be thoroughly familiar with the medical, psychological, and social implications and the technical limitations of the tests.

yes
3. College and university health officers should be aware of the procedures and qualifications of local and regional sources of testing for HTLV-III antibody.

yes
4. No student or employee should be tested, or referred for testing, for HTLV-III antibody unless: the testing is confidential or anonymous, positive results are confirmed by specific testing, counseling is provided, and informed consent is obtained.

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5. All persons desiring HTLV-III antibody tests require counseling both before and after the tests are done. No

one should have the test done unless pre-test counseling has been provided; no one should be given test results without the ready availability of post-test counseling. If such counseling is not available within the institution, there must be arrangements for it to be provided elsewhere.

good 6. Test results should never be provided by telephone, both to guarantee confidentiality and to facilitate post-test counseling.

7. Care providers must be aware that a variety of psychological reactions to either confirmed positive or negative test results can be expected. It is impossible to overstate the importance of sound knowledge, a non-judgmental approach, and a compassionate, unhurried attitude on the part of the care provider.

8. Adequate pre-test and post-test counseling require:

- a. the allotment of sufficient time
- b. a private setting
- c. guaranteed confidentiality *or anonymity*
- d. encouragement to the patient to ask questions, state fears, and verbalize reactions
- e. the availability of follow-up counseling, when appropriate and indicated

9. Information provided during counseling sessions should include:

- a. the technical and clinical capabilities and limitations of the test, and its cost
- b. the significance of positive and negative results
- c. the local procedures for handling confidential medical information
- d. the range of psychological impact and reaction to the test
- e. alternatives to testing: behavior modification without testing
- f. the best current information about the transmission of AIDS; behavioral guidelines

for avoiding transmission

- g. the possibility that confusing or conflicting information will be presented by other sources, especially the media
- h. resources for further information
- i. arrangements for local medical and psychological follow-up

10. The disposition and handling of test results and other confidential information are addressed in a separate document written by the ACHA Task Force on AIDS. Briefly, this information is protected by statutory standards; unauthorized disclosure to anyone creates liability. Whether the counseling sessions, the fact that the test was done, or the test results themselves should be recorded in the medical record are difficult issues. ACHA suggests that, given the potential for misuse of this information, care providers weigh carefully the importance of entering such records, except in circumstances of the medical evaluation of specific symptoms and/or signs suggesting HTLV-III infection. At the very least, patients must be informed in advance about exactly what information will be entered in the medical record and might therefore be available to others.

11. The American College Health Association strongly discovers the use of any test for HTLV-III antibodies as a mandatory "screening" procedure in any setting except blood donation. Especially, there should be no screening of:

- a. entering students, before or after admission
- b. any group of current students or employees
- c. those identified by supposition as being at high risk
- d. health sciences students
- e. food service employees, whether students or not

12. All health care providers should be aware that test procedures, interpretations, and reporting requirements may change over time; it is important to be familiar with current information and to stay in touch with developments in the field.

TO

Nancy

ROOM/STA.NO.

FROM

Lee

ROOM/STA.NO.

REPRESENTING

DATE

TIME

PHONE

☐ Telephoned☐ Please Call☐ Was In☐ Returned Call☐ Will Call Again☐ Wants To See You☐ Information

Note and

Reply

☐ Comment☐ Re-route☐ My Signature☐ Investigate☐ Return☐ Copy Me☐ Contact Me☐ File☐ Forwarded
Per Request

MESSAGE/REMARKS

Submitted it to Rich. Here's
hopin' -----

BY

MESSAGE

Nancy S.

CONFIDENTIAL-NOT A PERMANENT PART OF THE MEDICAL RECORD

Many factors must be considered in assessing your level of wellness. Among these are: 1) your risk of acquiring or transmitting any Sexually Transmitted Disease (S.T.D.) and 2) the use of psychoactive chemicals during sexual activity which can increase your risk of acquiring an STD. STD's considered here include, but are not limited to, gonorrhea, syphilis, chlamydia, Hepatitis B, Giardiasis, and AIDS. The first two questions are biographical in nature and are not part of the risk assessment score, but are intended to guide your provider in making the best possible appraisal of your health. The remaining eight are part of the scored behavioral risk assessment. Please be honest in responding to the following questions--we assure you that this document will be handled with the utmost confidentiality by authorized persons only. Please feel free to discuss the results with your provider. You may retain the survey for your own reference.

There are 10 questions listed below. Please check the answer that best describes your preferences or activities.

- A) How long have you been sexually active? _____
B) Your most recent consistent sexual partner experience
male _____ female _____ both male and female _____
- 1) How many partners have you had per month in the last year?
3 _____ 10 or more
2 _____ 3-10
1 _____ 0-3
- 2) How many partners per month in the year previous?
3 _____ 10 or more
2 _____ 3-10
1 _____ 0-3
- 3) The kinds of sexual contacts I have are:
3 _____ one time anonymous "tricks", groups, or prostitutes
2 _____ multiple times with the same partner(s)
1 _____ exclusive to my lover or spouse
- 4) I have sexual encounters or contacts most frequently
3 _____ in baths, bookstores, parks, "massage parlors", "spas" public restrooms
2 _____ in bars, autos, parties
1 _____ in my or my partner's home
- 5) The frequency I use drugs to enhance my sexual encounters.
3 _____ frequently
2 _____ occasionally
1 _____ rarely/never
- Please circle drugs used: poppers (amyl or butyl nitrites), alcohol, marijuana, hallucinogens (LSD, mushrooms), PCP, amphetamines, barbiturates,

- Quaaludes or _____ (please fill in others)
- 6) The frequency with which I inject myself with any of the above drugs is:
- 3 _____ often
 - 2 _____ occasionally
 - 1 _____ never
- 7) I have sexual encounters most frequently in:
- 3 _____ New York, LA, San Francisco, Miami, Wash. DC, Houston, Newark NJ, Atlanta
 - 2 _____ other large urban areas (Boston, Phila, St. Louis, Seattle, etc.)
 - 1 _____ small cities, towns, rural areas
- 8) Those kinds of sexual activities I practice most frequently are (please circle specific activities):
- 3 _____ unprotected vaginal or anal intercourse, oral-anal contact (rimming), direct fecal or urine contact (scat or water sports), or manual-anal (fisting).
 - 2 _____ "protected" vaginal or anal intercourse (use of condoms and spermicides), oral-genital contact (fellatio or cunnilingus).
 - 1 _____ masturbation, body rubbing, kissing

Add up the numbers from each question (1 to 8) and see the key below to determine your level of risk.

My score is _____

KEY:

- 17 or more: you are at high risk for developing STD's, including AIDS, and for possibly developing dependence on psychoactive substances. You should visit your provider every one to three months for a medical assessment and consider counseling for drug use.
- 12-16 points: you are at medium risk for developing problems and are encouraged to see your provider every three to six months.
- 11 or less: you are at low risk for problems and are encouraged to see your provider every six to twelve months.

This scoring system was designed to: 1) increase your awareness of STD's and the risk factors associated with acquiring or transmitting STD's 2) stimulate self-evaluation of your sexual lifestyle and 3) encourage your taking responsibility for your health and the health of your sexual contacts. You should see you provider immediately if you have questions or develop any symptoms of illness.

AIDS Update

NATIONAL GAY TASK FORCE
80 FIFTH AVENUE
NEW YORK, NEW YORK 10011

Mandatory Reportability, Contact Tracing, and HTLV-III Antibody Testing

The National Gay Task Force and other civil-liberties and AIDS-service organizations have grown increasingly concerned over the possibility that state governments might move precipitously towards (1) mandatory reportability of positive HTLV-III antibody test results and (2) institution of contact tracing to notify sexual (or needle-using) partners who may have been exposed to the virus. There is the danger that these measures will be resorted to as a concession to a public asking "that something be done" but without determining how effective overall the use of these public health powers would be in terms of AIDS prevention, and, if they are determined in any way desirable, how best they might be implemented. In so far as institution of either measure will tend to discourage individuals from having the test performed, they would ironically have the opposite effect of that desired by many of those in health departments who now propose these actions.

I. A. NGTF continues to regard mandatory reportability that extends to retention of identifying (as opposed to statistical) information, as neither justifiable nor desirable. Our position was stated originally in an update, dated 8/28/85, entitled "Reportability and HTLV-III Antibody Testing". The principle reasons for our opposition, in brief:

- o the traditional rationale for keeping names, therapeutic intervention, is absent.
- o epidemiological data about antibody testing can be collected without collecting names and addresses.
- o reportability will undermine the anonymity/confidentiality at the already successful HTLV-III testing sites (a.k.a. "alternative testing sites"), and thereby undermine the confidence of the communities at increased risk who make use of those sites.
- o the potential damage to individuals -- in terms of discrimination and stigmatization -- in the event of the unauthorized release of this information is far greater than for an ordinary STD. In Colorado, the one state that has thus far implemented reportability, a 17 year old boy was removed from regular school classes when his positive antibody status was discovered by school authorities.
- o it is not yet definitively known if the presence of antibody always indicates infectivity or risk to developing ARC/AIDS.

B. As a public health strategy contact tracing for AIDS -- asking those who test positive for HTLV-III antibody to name sexual and needle-sharing partners so that the health department may contact and counsel them -- does not offer the same clear benefit as it does in the case of diseases -- like

syphilis -- for which treatments are available. Its prevention value is less compelling since by this time in the epidemic, it is unlikely many sexually active or IV drug-using members of the groups at increased risk are unaware that they may have been exposed to the virus. The prevention value is clearer for those individuals who are not aware that they belong to a group at increased risk-- i.e., that they were the sexual or needle-sharing partners of possible carriers -- especially if they are women who might consider pregnancy at a later date.

Contact tracing suffers from some of the same potential pitfalls of reportability. It may have the effect of discouraging members of the affected communities from visiting HTLV-III testing sites (a.k.a. alternative testing sites) or health department-run STD clinics, where education and voluntary testing is available, if they imagine that they may find themselves in the situation of being pressured to give names and addresses of contacts. If public health representatives are knocking on doors (or otherwise searching people out) then the possibility of this provocative information, far more stigmatizing than is the case for any ordinary STD, falling into hands of unsympathetic parties, is increased. Aggressive pursuit of the contact tracing model is inimical to building a bond of trust that promotes cooperative interaction between attendees of testing sites or STD clinics and public health representatives.

Potentially, a policy of contact tracing might have the unfortunate effect of encouraging anonymous sexual contacts over those that involve a process of discussion and familiarization between prospective sexual partners, if the individuals in question fear that divulging names and identifying information would ultimately place them at risk to being contacted by public health authorities. Those conducting AIDS prevention education regard the familiarization process as conducive to responsible decisions about adherence to safe sex guidelines.

Both reportability and contact tracing are explored further in a Question and Answer section beginning on page 5.

II. New CDC Letter Addresses Reportability, Contact Tracing, and Other Issues. On December 6, 1985, the Director of the Centers for Disease Control, Dr. Jim Mason, sent a memorandum to state and territorial health officials that explores what additional options might be taken to encourage prevention through use of the HTLV-III antibody test(s) and includes a discussion of contact tracing and reportability.

A. Fortunately, the recommendations adopt an appropriately cautious stance on reportability, stating merely that "we need to begin evaluating the implications of requiring some kind of reporting of positive HTLV-III/LAV antibody results to the health department...Requiring reporting of positive results, especially with personal identifiers, needs to be weighed against the possibility that such requirements might discourage high-risk persons from agreeing to non-anonymous testing." This will hopefully have a restraining effect upon state health departments -- there have been signs in recent months that other states such as Arizona might follow Colorado's example -- overly eager to embrace mandatory reportability that extends to the listing of names and addresses. The CDC tacitly concedes that reportability need not extend to collection of names and addresses:

"If testing and notification does not include personal identifiers, notification could still provide valuable statistical data to indicate the prevalence of infection and to assist in planning and evaluation, such as for coordinated programs of community-based health education and risk reduction."

B. The CDC in its memorandum discusses the relevance of the classic contact tracing model to curbing HTLV-III infection but ultimately they "recommend a departure from this approach with HTLV-III/LAV patients at this time." They suggest, after noting the absence of therapeutic intervention for infection, "that identifying information not be sought for partners [who may have been exposed]." Under their suggested scenario "the patients themselves would be encouraged to make as many referrals [for testing and counseling] as possible." Only if "the patient registers a preference for the counselor to contact and refer known partners...[then] sharing identifying information would be necessary."

C. Another recommendation made by the CDC is that health departments should now consider steps to "openly offer and encourage people to have voluntary HTLV-III/LAV testing in STD clinics and in clinical settings where IV drug abusers or prostitutes are seen." It is in this context that a modified contact tracing model is suggested.

D. Fortunately, the CDC guidelines do give some emphasis to the confidentiality issues raised by their recommendations: they wisely recommend that health departments should be considering the advisability of "Assuring that your regulations and statutes protecting the confidentiality of all health department records relating to infection and other STDs include protection from disclosure through litigation, or any other disclosure not agreed to by the patient." Further, as regards contact tracing in particular, they advised that "in states where such information is not protected from disclosure through litigation, e.g., subpoena, we would recommend against maintaining formal name-identified records concerning such referrals."

III. Recommendations for Responding to the CDC Guidelines: These guidelines are reasonable in so far as they make some concession to the need for sensitivity in the use of contact tracing and caution in advancing towards reportability of names and addresses.

A. The recommendation in favor of making the test available in STD clinics is of concern in that HTLV-III testing requires a sensitivity that is readily provided at most of the special testing sites, but which is in many cases different from that cultivated in your typical STD clinic, where the atmosphere can verge on the coercive. These special sites, established originally as "Alternative Testing Sites," in most states already provide a confidential and in many cases totally anonymous testing procedure -- the ideal from the point of view of protecting against abuses -- and in most cases careful pre- and post-test counseling. STD clinics, on the other hand, are used to providing all sorts of tests, but none as potentially alarming or provocative as this, and usually in a bland factory-like manner, without careful counseling to guard against misinterpretation of results or special precautions to guard against disclosure to unauthorized parties. Consequently, the special HTLV-III testing sites (where distinct from STD clinics) are better-suited to continue as the primary outlets for

testing. This would not preclude STD clinics from providing information about the test and AIDS prevention.

B. Contact tracing may be justifiable when there is reason to believe that the sexual or needle-sharing contact may not be aware that s/he may have been exposed. Clearly it is more likely to be successful if the integrity of the confidential (and preferably anonymous) testing procedures at HTLV-III testing sites are preserved, i.e., if mandatory reportability of names and addresses is avoided, since the bond of trust between the antibody positive individual who is interviewed and the testing center personnel is enhanced. Ultimately contact tracing, however it is conducted, depends on voluntary cooperation; intimidation will never substitute for trust and sensitivity in eliciting that cooperation.

C. The CDC is correct that the notification of contacts is best left to the antibody positive individuals themselves. Thorough counseling should be made available to those who are contacted, advising them of the possibility that they are infected and infectious, telling them of the availability of testing for antibody and the limitations of these tests.

D. Besides counseling, in those selected cases where notification may be justified and where the antibody positive individual asks the health department to notify the contact, confidentiality protections must be carefully constructed to reduce the possibility that the identity of the antibody positive individual is revealed to unauthorized third parties, including the contacts. The CDC's cautionary words to state and territorial epidemiologists on the need for confidentiality of AIDS-related records are welcome as are their recommendations for protecting records from release through litigation. It should be noted that to the best of our knowledge no state has yet made its STD records subpoena-proof. This should be a condition attached to any consideration of HTLV-III/LAV testing using personal identifiers.

E. As already noted, mandatory reportability can be implemented without the hazard of confidentiality abuses if the data required is limited to statistical information needed by epidemiologists to chart the development of the epidemic and excludes name, address, and social security number. If ability to notify antibody positive persons for the purposes of treatment (when it becomes available) is viewed as the pivotal issue in any jurisdiction considering mandatory reportability, case reports of antibody positive individuals could be coded by random alphanumeric sequence (or possibly using the not entirely random Soundex system), with the key to the identifying information remaining in the hands of the treating physician, so as to allow for eventual notification should there be a compelling reason to do so at a future date.

F. We recommend that organizations concerned with civil rights aspects of AIDS in the various states involve themselves in advising health departments that will receive and consider the 12/6/85 CDC recommendations on reportability, contact tracing, and on making the test available in the standard STD clinic format.

Keep in mind, the recommendations contained within the CDC letter are non-binding and are not being imposed upon any local or state health department. Therefore, at the discretion of these health departments and

the public health policy boards and political representatives to whom they report, these suggestions can be both improved upon, or at the other extreme, disregarded in favor of more insensitive techniques that in the final analysis may not serve the goal of AIDS prevention.

VI. Mandatory Reportability and Contact Tracing; Question and Answer Section:

Q: Since mandatory reportability and contact tracing are strategies that have traditionally been at the disposal of epidemiologists and public health officials, why shouldn't they be employed to their fullest extent?

A: While it may be reassuring from a public relations perspective for public health officials to "pull out all the stops" and employ all options at their disposal, the appropriateness of specific public health measures must be judged calmly and intelligently, taking into account their impact on HTLV-III testing sites -- which are working well -- their potential for preventing future infection, and also their potential for causing harm through misuse, and for shaking the bond of trust that is necessary between the affected communities and public health departments. Also, it is not yet clear that the test itself is specific for infectivity or the danger of developing ARC or AIDS. In justifying his action in Colorado, Dr. Vernon, the director of that state's Department of Health, referred to a need to "say to an anxious public that we are doing what we know how to do." However, officials should realize that clumsy public health policy that has the effect of driving the disease underground is bad public health policy and cold comfort indeed to an understandably concerned public.

* * *

Q: If the health department gives its assurance that mandatory reportability and contact tracing will not lead to unauthorized release of names for the purposes of single case discrimination or quarantine, why oppose this effort?

A: It is important to keep in mind that however trustworthy and conscientious such a civil servant or appointee may be, s/he may not be in office next year or the year after, or may be forced to take action by a politically-motivated superior or a state/local legislature. Furthermore, maintenance of confidentiality ultimately depends on a network of individual health department employees; the possibilities for breaches are real and the potential damage for individuals or stigmatized groups is enormous.

* * *

Q: But epidemiologists argue that they need the data that reportability would yield to track the extent of the epidemic.

A: The statistical needs of epidemiologists could still be satisfied by allowing access to cumulative test results that do not contain identifying information linked to any particular individuals.

* * *

Q: Will it not be desirable to have a list of antibody positive persons so that when treatment for HTLV-III infection becomes available, it will be possible to let them know immediately?

A: The possible eventual notification value is undermined by the fact that the test is not known definitively to correlate with presence of significant quantities of the live virus capable of attacking and depleting the T-Cells. Also, it is not very plausible to imagine that someone who is antibody positive for HTLV-III would not learn of and act to gain access to such treatment.

* * *

Q: What has been the effect of mandatory reportability in Colorado, the one state that has implemented it?

A: It is reported that gay men are now shunning the test or are giving false names to prevent their going onto the registry. These repercussions had been predicted by the Colorado AIDS Project and ACLU in that state when they testified against mandatory reportability. It is reported that the health department is now tacitly condoning the use of false names -- de facto anonymity -- by no longer requiring ID when individuals are tested.

* * *

Q: How reliable are the blood tests that would provide the data on which reportability and contact tracing would rest?

A: The usefulness of the various tests (ELIZA, Western Blot, or Immunofluorescence assay [IFA]) for determining who is infectious and who is definitely at risk for becoming ill at some point later in life is not definitively known. As long as the diagnosis and prognosis for antibody positive persons is imperfectly understood, or until a test(s) is available that clearly indicates carrier status, then the arguments for reportability and contact tracing are not utterly compelling. Though the CDC is inclined towards making blanket statements endorsing the test as a screen for identifying those who are carrying the virus, spokespersons for the FDA (which licenses and regulates use of the tests) have been more cautious in their assessments.

* * *

Q: Which states have formally considered making reporting of positive HTLV-III/LAV antibody test results mandatory?

A: New Jersey held hearings in May on mandatory reportability and, after hearing the evidence in favor and the disadvantages, rejected this proposal. In August, Colorado went against objections from local organizations and made reportability mandatory effective in October. In November, New Mexico considered but ultimately tabled a proposal for reportability. South Carolina recently decided to make the test reportable effective in January. Arizona is now said to be considering mandatory reportability.

* * *

Q: Could insurance companies, employers, or the military, gain access to lists through legitimate means?

A: As things stand now, even if mandatory reportability became widespread, it is highly unlikely that they could gain access. Only a major reversal of past precedent could bring about this draconian vision. However, inadvertent disclosure cannot be ruled out; all security systems are vulnerable to failure; to say otherwise is pure hubris.

* * *

Q: Could mandatory reportability create a list that might be used to initiate quarantine procedures or threaten specific individuals with such measures?

A: In theory, yes. However, mass quarantine of all antibody positive individuals would be highly impractical; if only 25% sought testing, the government would have to intern or otherwise monitor/confine upwards of quarter of a million of people. It would unfortunately be more feasible for local health departments to use their list to harass individuals. In San Antonio the health commissioner decided, based on a report that one or two individuals were placing others at risk, to write a threatening letter to all the persons with AIDS in his jurisdiction. Theoretically, the same high-handed action could be taken against those who are antibody positive, (particularly in low incidence areas, where their number are fewer), and with the same attendant risks that the letter would fall into the hands of unsympathetic third parties.

* * *

Q: Isn't it true that health departments have a good record in protecting the confidentiality of those who visit STD (Sexually-Transmitted Disease) clinics and doesn't this indicate that we can have equal confidence in these protections as regards AIDS?

A: Yes, they do have a good record as regards ordinary STDs. But AIDS carries a stigma that far exceeds that of virtually any other illness. Public fear of casual contagion, though without medical justification, would likely result in unprecedented pressure being placed on the system of confidentiality such as that typically used in public STD clinics. Driven by such unwarranted fears, and perhaps abetted by prejudice against gay men, local health department functionaries with access to a registry of test results might conceivably feel justified in leaking the name of an antibody positive individual holding a position as a teacher, food-service, or health care worker. Mandatory reportability would make breaches of test result confidentiality more likely and would require the "alternative testing sites" that provide antibody testing to abandon the best form of protection: anonymous testing procedures.

* * *

Q: What might be the effect of mandatory reportability and contact tracing on the blood banks on which we all depend?

A: Mandatory reportability and contact tracing might have a deleterious effect on the ability of blood banks to attract and maintain eligible donors. Though the rate of positivity among blood donors has been less than one half of one percent, some members of the non-high-risk group public might be deterred from giving blood if they felt there was even a slight chance that their names would be reported to state health authorities and connected with AIDS or that they would be interviewed regarding their sexual contacts. Recall the that in some cities a segment of the blood donating public for a time shunned donation out of a totally unfounded fear that they might get AIDS from a dirty needle, resulting in a 10% drop in blood supplies.

Prepared 12/19/85.

#

The NGTF AIDS Program is supported in part by grants from the NGTF Fund for Human Dignity, the Gay Men's Health Crisis, and the AIDS Action Council.

AIDS ANTIBODY TESTING

at
Alternative Test Sites

A Program of the San Francisco
Department of Public Health

Information to help you make an informed
decision about whether or not to take the test.

Introducing the **AIDS ANTIBODY TEST** at Alternative Test Sites in San Francisco

The AIDS ANTIBODY TEST is available free of charge at Alternative Test Sites in San Francisco. This is a program of the San Francisco Department of Public Health. The AIDS antibody test detects the presence of antibodies to the AIDS virus by using a simple blood test. The test has been made available to keep potentially infectious blood out of the blood supply.

This is **not** a test for AIDS. The test does **not** tell you if you have AIDS or any AIDS Related Condition (ARC); it **does** show whether you have been infected with the virus which can cause AIDS.

Infection means that a virus has been retained in your body. If you are infected with the AIDS virus, your body will produce antibodies, which can be identified by the AIDS antibody test. You cannot be infected by casual contact with the virus. Infection can only occur when the virus is transmitted through intimate sexual contact, sharing needles, or blood transfusion.

Many people are concerned that they might face insurance or employment discrimination if the result of their test were revealed. Although the test is available at other locations, your anonymity is guaranteed if you take the test at an Alternative Test Site. You can get test results at Alternative Test Sites in San Francisco without losing your privacy or revealing your personal identity.

Your decision whether or not to take this test is a difficult one. You must decide for yourself. This publication provides information to help you make an *informed* decision. If you have questions which are not answered here or at the Alternative Test Site, contact the **Bay Area Physicians for Human Rights (415-673-3189)** or the **San Francisco Medical Society (415-567-6234)** for referral to a physician knowledgeable about AIDS, or call the **San Francisco AIDS Foundation Hotline (415-863-AIDS)**.

Test Procedure

At Alternative Test Sites

Anonymity is built into the Alternative Test Site system. You do not give your name, address, social security number or other official identification numbers.

To take the test at an Alternative Test Site you need to make an appointment by telephone beginning June 24, 1985 (call **415-621-4858** 12-8 pm Monday-Friday). In San Francisco, the Alternative Test Sites are located at Health Centers 1, 2, and 5. The entire visit, including education, will take approximately one hour. You will need to return to the Alternative Test Site in person two weeks later to get your test result. The test and all education, counseling and referral services are free at Alternative Test Sites.

When you call to make an appointment for testing, an operator will give you an appointment number. This number cannot be traced back to you. When you go to the Alternative Test Site you will be given further information about the test. Afterwards, if you decide not to take the test, you may leave. If you decide to take the test, you will be given a new number to identify your blood sample. This number does not reveal your personal identity.

In two weeks you will return to the test site to get your test result. Upon presentation of your number, a health counselor will give you your test results and explain them to you in private. You will also receive a referral list in case you wish further attention.

To receive counseling after you take the test but before getting results, contact Community Mental Health Services (415-558-4387).

Confidentiality and Anonymity

Confidentiality is an agreement that information about you will not be disclosed without your consent. Anonymity is a condition in which your personal identity is unknown to others. Your anonymity is guaranteed if you are tested at an Alternative Test Site. If you take the test anywhere else, your anonymity may not be guaranteed, except in some research programs.

Should I Take the Test?

Before you decide to take the test, stop for a moment to consider how you would feel if you received a positive result and how you would feel if you received a negative result. If you believe that you may be emotionally overwhelmed, you may not want to take the test.

The test will not tell you:

- ▶ if you have AIDS or an AIDS Related Condition (ARC).
- ▶ if you will develop AIDS or ARC in the future.
- ▶ if you are immune to AIDS or ARC.
- ▶ if you are healthy.

People who do not want to know the result should not take the test. People who feel unwilling or unable to cope with the implications of the result should not take the test.

The following people should consider taking the test:

- ▶ People who want to know if they're infectious.
- ▶ People who want information that can reinforce safe, healthful behavior.
- ▶ People who want to know if they have been infected with the AIDS virus through sexual contact, shared needles, or transfusions.
- ▶ People considering pregnancy if one or both partners might be at risk for AIDS.

Whether or not you take the test, if you may be at risk for AIDS, you should not engage in practices which can transmit AIDS.

Test Results

And What They Mean

The AIDS antibody is a protein naturally produced in the body in response to the presence of the AIDS virus. The virus is called by several names: HTLV-III, LAV and ARV.

A positive test result indicates that the antibody *has* been found in your blood. A negative test result indicates that the antibody has *not* been found in your blood. The test is not completely accurate. A small percentage of people tested may be told that they have been infected by the virus when in fact they have not. In addition, a small percentage of people will receive a negative test result when in fact they have been infected with the virus.

A Positive Test Result

*If you test positive it **does** mean:*

- ▶ Your blood sample has been tested more than once and the tests indicate that antibodies to the AIDS virus are present.
- ▶ You have been infected with the AIDS virus and your body has produced antibodies.
- ▶ Researchers have shown that most people with AIDS antibodies have active virus in their bodies. *Therefore, assume you are contagious and capable of passing the virus on to others.*

*If you test positive it **does not** mean:*

- ▶ That you necessarily have AIDS or an AIDS Related Condition (ARC).
- ▶ That you will necessarily get AIDS or ARC. (You can reduce your chance of getting AIDS by avoiding further contact with the virus and maintaining a healthy lifestyle.)
- ▶ That you are immune to AIDS.

Therefore, if you test positive:

- ▶ Protect yourself from any further infection.
- ▶ Protect others from the virus by following AIDS precautions in sex, drug use and general hygiene.
- ▶ Consider seeing a physician for a complete health evaluation and advice on health maintenance.
- ▶ To improve your chances of staying healthy, avoid drugs and heavy alcohol use, maintain good nutrition, and avoid fatigue and stress.
- ▶ Do not donate blood, plasma, sperm, body organs or other tissue.

A Negative Test Result

If you test negative it means that no antibodies to the AIDS virus have been found in your blood at this time. There are three possible explanations for this:

- ▶ You have not been infected with the virus.
- ▶ You have had contact with the virus but have not become infected and therefore have not produced antibodies. However, repeated exposure to the AIDS virus will increase the likelihood that you will become infected.
- ▶ You have been infected by the virus but have not yet produced antibodies. Research indicates most people will produce antibodies within 2–8 weeks after infection. Some people will not produce antibodies for six months or more. A very small number of people will never produce antibodies.

*If you test negative it **does not** mean:*

- ▶ That you have nothing to worry about. The AIDS epidemic has not yet peaked.
- ▶ That you are immune to the virus.
- ▶ That you have not been infected with the virus. You may have been infected and not yet produced antibodies.

How Is AIDS Transmitted?

AIDS is transmitted from person to person most commonly through sexual contact in the same manner as other sexually transmitted diseases or through direct blood to blood contact such as via shared needles. It is **NOT** transmitted through casual contact such as close proximity, sneezing or touching.

What Groups Are Known To Be at Risk for AIDS?

- Gay and bisexual men
- Intravenous drug users
- Hemophiliacs
- Women or men who have had unsafe sexual contact or have shared needles with someone who may have been infected with the AIDS virus.
- Babies born to parents in any of the above groups.
- People who received blood transfusions between 1979 and 1984 have a very slight risk of infection.

In summary:

If you are currently healthy and you test positive:

- ▶ You will not necessarily develop AIDS or ARC.
- ▶ You *can* increase your chances of staying healthy.
- ▶ You are probably contagious and can spread the virus to others through sexual contact, blood donation, shared needles or pregnancy (to the unborn child).

If you are currently healthy and test negative:

- ▶ You are not protected from future infection or illness.
- ▶ You are probably free of the AIDS virus. If you have doubts about having yet produced antibodies, avoid contact with the virus, wait six months and be re-tested.

Whether you test positive or negative:

- ▶ Be careful. Don't contract or transmit the virus.
 - Follow safe sex guidelines in all risk situations.
 - Do not share needles.
- ▶ If you have any symptoms of AIDS or ARC, consult a physician or visit an AIDS screening clinic.
- ▶ Because the long-term consequences of infection by the AIDS virus are not known, we urge everyone to maintain adequate health insurance.

Recommendations for Avoiding Transmission of the AIDS Virus

Males and females, heterosexual, bisexual or homosexual, may acquire or transmit AIDS through intimate sexual contact. Condoms (rubbers) have been found effective in stopping other viruses such as herpes and cytomegalovirus (CMV). Their use is recommended. In risk

situations, no one should allow their semen, blood, urine, feces or vaginal secretions to enter the body of another person.

Personal implements such as razors and toothbrushes that could become contaminated with blood should not be shared.

If you decide to take the test in San Francisco, telephone **415-621-4858** 12-8 pm Monday-Friday to make an appointment. For Alternative Test Site locations outside San Francisco, call the **AIDS Hotline** at **415-863-AIDS** or **800-FOR-AIDS** (in Northern California).

To receive an individualized health consultation or to participate in a support group, call the **AIDS Health Project** at **415-626-6637**.

For further information about AIDS, contact the **San Francisco AIDS Foundation Hotline (415-863-AIDS)**, or contact **Bay Area Physicians for Human Rights (415-673-3189)** or the **San Francisco Medical Society (415-567-6234)** for a referral to a physician knowledgeable about AIDS.

The information provided in these pages has been compiled by the **San Francisco AIDS Foundation** under contract from the **San Francisco Department of Public Health**.

Published June, 1985

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San Francisco, CA 94103

**Hotline Information: 415-863-AIDS
in Northern California: 800-FOR-AIDS
TDD: 415-864-6606**



What happens when you become infected with the AIDS virus?

AIDS stands for Acquired Immune Deficiency Syndrome, a disease caused by a virus which breaks down a part of the body's immune system. This breakdown leaves the body vulnerable to a variety of unusual infections. Not everyone infected with the virus will develop AIDS. There are several possibilities:

- The majority of infected people will develop antibodies to the virus yet remain healthy. They will display none of the symptoms of AIDS. Research indicates that most people in this group can transmit the virus to others by shared needles or intimate sexual contact. The long term effect of infection in healthy, antibody-positive people is not known.
- A smaller group of people who are also antibody-positive will develop some of the symptoms of AIDS. These people are diagnosed as having an AIDS Related Condition (ARC). They may exhibit mild to severe symptoms such as swollen lymph nodes, unexplained, persistent diarrhea, unintentional weight loss, mild or intermittent fever, drenching night sweats, fatigue, and/or yeast and fungus infections.
- An unknown percentage of infected, antibody-positive people will develop AIDS. A diagnosis of AIDS is made only after finding specific life-threatening infections or malignancies that do not normally occur in healthy people. The two most common diseases associated with AIDS are *Pneumocystis carinii* pneumonia (PCP) and Kaposi's sarcoma (KS).

RISK FACTORS AND RELATIVE DANGERS OF SEXUAL PRACTICES

A/ Types of Sex Acts

Anal or Vaginal Penetration w/o condom
Rimming
Scat
Fisting
Piercing, biting, whipping and other S&M activities to the point of letting blood
Swallowing semen

In general, any form of sex in which blood, semen, urine, feces and (possibly saliva), pass from one partner to another and any acts which cause trauma to body tissues.

Oral Sex if cum is not swallowed
French Kissing
Anal Sex with condoms, especially if penis is withdrawn before orgasm.
Water Sports may be low risk if urine does not contact broken skin and does not go in eyes, mouth, nose or rectum

Jacking Off
Hugging
Body Rubbing
Cuddling
Caressing
Massage
Fantasies
Costumes
Imagination
Social (Dry) Kissing
Phone Sex
Mouth/Body contact is safe if you avoid body cuts, abrasions, etc.

B. Frequency of Sexual Contact with Different Partners

4 or more in a month

Between 1 and 3 different partners per month

ONLY ONE PARTNER

C. Where You Meet Your Partner

Backroom Bars
Bathhouses
Bookstores
(tricking in the dark)

Public Toilet
Parks (lighted areas)
Motor Vehicles

Parties
Private Homes

D. Questions on Hygiene: How often do you wash with soap and water before and after sex? Urinate immediately after sex? Make proper use of condoms?

Rarely

Occasionally

Always

E. How often do you use the following drugs either before, during or after having sex: poppers, alcohol, marijuana, cocaine, opiates, hallucinogens, amphetamines, barbiturates, "Angel Dust", tranquilizers?

Frequently

Ocassionally

Never

F. Geographical area where you and your partner(s) live, travel, have sex?

San Francisco
Miami, Houston
NYC, LA
Chicago

Other large urban areas, such as San Antonio

Small cities and towns; rural areas.

G. Type of Sexual Encounter

Anonymous encounters or anonymous Group Sex

Sex within a small closed group, or sex with another who has multiple partners

Mutually sticking to one partner, monogamy

HIGH RISK

MEDIUM RISK

LOW RISK

Know your partner.

COMMUNICATE!!! Learn to say no. Limit your number of partners. Enjoy more time with fewer partners. Romance is "in" and promiscuity is "out". Intimacy must become the new mind-set for the 80's. Remember, you are fighting for our lives.

Make arrangements beforehand to have safe sex, and have only safe sex. Denial of this serious problem will work against the relationship in the long run. Exchange names and phone numbers, or at least give yours. Tactfully find out what you can about the overall health of your partner before initiating sexual activity. If you shower together first or undress in a lighted area, you have a chance for an unobtrusive examination for signs of disease. Washing your hands, genitals, and anus before and after having sex can reduce the risk of contracting certain STD's, as can urinating immediately after sex. However, RIMMING cannot be made safe by washing! A rectal enema or douche before anal penetration can actually INCREASE risk for both partners.

Use Proper Lubrication

The ideal lubricant is water-soluble, non-perfumed, colorless, and comes in a closed dispenser such as a hand pump that cannot be contaminated at the time it is used.

Be sure to use a condom whenever you ejaculate inside your partner's mouth or rectum. You can reduce the risk even further by withdrawing before you ejaculate. When having anal sex, use only high-quality condoms and plenty of water-soluble lubricant. It is easier to break a condom during anal sex than with vaginal sex, and oils and Vaseline deteriorate latex rubber.

Another Word about Recreational Drugs

Drugs used with hypodermic needles puts the user at very high risk. AIDS can be spread by sharing hypodermic needles with someone who has AIDS. You should never use needle drugs; at the very least — DO NOT share needles!

Intoxicants also increase your risk by reducing your capacity to think rationally, which in turn can impair your resolve to engage only in low-risk sexual activity. This impairment of judgement leads possibly to high-risk activities. Certain drugs diminish the user's perception of pain, and can lead to tissue trauma during sex, which greatly increases risk of your exposure to AIDS.



**SAN ANTONIO
AIDS FOUNDATION, INC.**

P.O. Box 120113
San Antonio, Texas 78212-9313

AIDS HOTLINE
512/699-0047

Guidelines and Recommendations For Good Health

Know your own body and take good care of it.

A. Use common sense and follow Granny's advice:

- Get adequate rest and sleep.
- Eat the right foods.
- Get plenty of exercise.
- Eliminate as much stress as possible.
- Avoid alcohol, tobacco, and drugs. Keep your head clear. Drugs impair your judgement. Toxic substances may inhibit the immune system.
- Use only your own toothbrush and razor, since blood or other potentially infectious materials may be unwittingly shared.

B. Be aware of the messages your body gives you. Routinely examine yourself for physical signs of infection. Any persistent, abnormal bodily function should be viewed with suspicion. Your best chance of being properly diagnosed and treated comes through seeking medical care as soon as possible.



San Antonio AIDS Foundation, Inc.
P.O. Box 120113
San Antonio, Texas 78212-9313

SAAF HOUSE:

A place of refuge for those people with AIDS who have no where else to go is desperately needed in San Antonio. At first, this facility may only provide non-medical services. As more funds are raised and proper health care professionals are available, the SAAF Board envisions a hospice home. The problems created by AIDS appears to be increasing. The time is now!

San Antonio AIDS Foundation, Inc



P.O. Box 120113
San Antonio, Texas 78212-9313

AIDS HOTLINE:
(512) 699-0047

Hotline Hours: 9:00 a.m. to 6:00 p.m.
other hours on answering machine

Meetings:
Last Thursday of every month at 7:30 p.m.
Places to be announced

The San Antonio AIDS Foundation (SAAF), is a non-profit community service organization created to address all concerns arising from Acquired Immune Deficiency Syndrome, or AIDS.

GOALS

● **Education:** To educate the entire community concerning all issues surrounding AIDS in hopes of alleviating fear and curbing the spread of this disease.

● **Social Service:** To provide friendship care to people with AIDS, their families and friends by sharing love and support and a listening ear.

● **Research:** To promote the efforts of AIDS research organizations in participation with other nationwide AIDS groups.

● **SAAF House:** To make available for people with AIDS who have no other available housing, a facility where non-judgemental care & support will be provided.

Address all contributions to:

SAAF House Project
P.O. Box 120113
San Antonio, Texas 78212-9313

Who May Use Our Services?

Any person with AIDS, AIDS related Complex (ARC), or anyone concerned that they may have AIDS.

Any family member of friend of a person with AIDS.

Health care professionals requesting information or direct service for a patient.

High risk groups requesting information on how to reduce their risk.

General community requesting general information about AIDS.

COMMITTEES

EDUCATION:

- Creates & distributes pamphlets and posters.
- Conducts AIDS risk reduction seminars.
- Teaches people how to deal with all aspects of the disease including epidemiology, psychological issues, and nursing management.
- Assists health care professionals through educational literature and in-service programs.

SOCIAL SERVICE:

- Addresses the immediate concerns of people with AIDS to assist in obtaining food, housing and financial support.
- Trains "buddies" who will provide friendship support to people with AIDS and their families and friends, through daily telephone contact and weekly home or hospital visits.
- Sets up counseling services for people with AIDS, their families and friends, and also for SAAF volunteers.

FUNDRAISING:

- Raises funds to support the Foundations operations.

HOTLINE:

- Trains and prepares volunteers to answer all calls.
- Makes certain the phone is answered between 9 a.m. and 6 p.m.

_____ I want to volunteer my time as a buddy.

_____ I want to help in educating the community.

_____ I want to help in fundraising.

_____ Place my name on the SAAF mailing list.

Name _____
Address _____
City/State _____ Zip _____
Phone _____ Area Code _____

All names, addresses and phone numbers are confidential.

_____ Enclosed is a donation to the SAAF general fund. This money goes to education and social services.

_____ Enclosed is a donation for the SAAF House Project.

Address: Professional Friends, Inc.; San Antonio AIDS Foundation, Inc.; or SAAF



January 4, 1986

Dear Ms. Shaw:

Thank you for your interest in our "Safe Sex" pamphlet.

We are overwhelmed and impressed at your wide array of pamphlets.

We have been in operation since June 1985 and have found San Antonio to be extremely challenging. However, in spite of many obstacles, we have been able to produce educational ~~and~~ brochures, put on seminars and provide adequate social services through volunteers. Our main social service project is to start a residence home for people with AIDS. This project will be mainly funded by the Catholic Church.

If you would like more information,
please contact us.

yours very truly,

Beverly Smith
President of SAAF, Inc.

Prototype Format .
-For-
Counseling People with Seropositive HTLV-III
Antibody Test Results

I. Introduction

- A. Introduce yourself and your professional role.
- B. Define the purpose of the session.
- C. Explain and emphasize the confidential nature of the discussion.

II. Assessment

- A. Inform the person of the test result. [If the individual has not received pretest counseling, it may be advisable to provide information about the test (Section III) prior to informing the patient of the test result.] Assess the person's understanding of the test result by asking, "What do you know about the meaning of a positive test?"
- B. If the risk status of the person is unknown, assess the risk status by asking, "Why did you decide to have the test performed?"
- C. If the person does not indicate that he/she may have been possibly exposed, tell him/her:
 - 1. Let's discuss some personal information so that we can best determine what this test might mean for you. This information about your medical and sexual history is confidential."
 - 2. People at increased risk of exposure to the virus are those who:
 - o are gay or bisexual males.
 - o inject drugs such as cocaine or heroin.
 - o have been treated for hemophilia.
 - o have received blood transfusions.
 - o have immigrated to the United States since 1977 from countries with a high incidence of AIDS.
 - o have symptoms consistent with AIDS or AIDS-related complex (ARC) such as persistent diarrhea, weight loss, or lymphadenopathy.
 - o are sex partners of people in any of the above groups, or sex partners of people with AIDS or positive HTLV-III antibody tests.
- D. Ask the person, "Based on this information, do you believe that you have been exposed to the virus?"

III. Information About The Test

- A. Explain that this is a test for antibodies to the virus which causes AIDS, but that most individuals with a positive test neither have AIDS nor will develop it in the next few years.
- B. Advise that the meaning of test results will be clearer after qualified medical followup.
- C. People with no history of possible exposure or symptoms (low risk)
Some people will have a positive test even though they are not infected with the virus. The proportion of false positives is higher in this group (low risk). Other people whose tests are positive are truly infected with HTLV-III and can transmit the virus to others.

D. People with a history of possible exposure or symptoms (high risk)

1. A positive test probably means infection with the HTLV-III virus.
2. AIDS occurs IF the virus overwhelms the body's defense system -- stress IF, because not everyone with the virus develops AIDS.
3. A person's ability to avoid repeated exposure to different infections, including other STD like syphilis, gonorrhea, and herpes, as well as HTLV-III, may have an influence on whether or not AIDS will develop.
4. Sexual activity in which body fluids are shared place a person at greater risk for infection and make it possible for a person to pass the virus to others.

IV. Prevention Recommendations

Discuss the following recommendations. Begin by asking, "What do you think you can do to avoid exposure to infections and passing the virus to others?"

- A. To reduce the risk of exposure to infections and of spreading the virus to others, always use "safe sex" practices to prevent the passing or receiving of body fluids - especially blood, semen, saliva, urine, or feces. Use condoms.
- B. Reduce the number of sex partners, even if "safe" sexual activities are involved, to further reduce the chances of being exposed to infections and of infecting others.
- C. Inform sex partner(s) so that they may also take steps to reduce their risk of infection.
- D. Avoid sharing needles to prevent the transfer of the virus from person to person.
- E. Don't share toothbrushes, razors, etc., which could become contaminated with body fluids.
- F. Use routine detergent and water cleaning procedures for household materials and personal belongings. If a significant amount of blood, feces, or vomitus contaminates a surface, additional cleaning with a 1:10 solution of chlorine bleach or a hospital strength disinfectant is recommended.
- G. Refrain from donating blood, plasma, body organs, other tissue, and sperm.
- H. Avoid pregnancy for self (or spouse).
- I. When seeking medical care, inform doctors and dentists of antibody status so they can take measures to prevent the spread of the virus.

Summarize by noting that although this person probably has the virus, following the prevention recommendations may reduce the risk of getting additional infections. This may influence whether AIDS will develop and will reduce the likelihood of passing the virus to others.

V. Medical Referral

- A. Explain to the individual that he or she is in need of medical followup to better determine the meaning of the test result. This medical care might include:
 1. Medical, sexual, and social history;
 2. Physical exam; and
 3. Additional laboratory tests.
- B. Make an appropriate referral to a physician or medical facility including:
 1. Name and address of facility;
 2. Phone number and hours of operation; and
 3. Cost.

VI. Conclusion

- A. Address any questions which the person has.
- B. Reinforce the patient's commitment to seek medical care and follow prevention recommendations.
- C. Provide a handout which reinforces the prevention recommendations.
- D. Provide the name, address, and phone number of a professional counseling facility to all patients. (Some patients may desire or need additional counseling at a later date.)

ALTERNATE SITE ANTIBODY TESTING PROGRAM

GOALS AND OBJECTIVES FOR PRE-TEST HEALTH EDUCATION

GOALS: TO PROVIDE AN INFORMATIONAL PROCESS SO CLIENTS CAN MAKE AN INFORMED DECISION ABOUT THE VALUE OF THE AIDS ANTIBODY TEST FOR THEMSELVES.

TO PROMOTE THE ADOPTION OF AIDS RISK REDUCTION BEHAVIORS AMONG CLIENTS WHO PARTICIPATE IN THE PRE-TEST HEALTH EDUCATION GROUP AT THE ALTERNATE TEST SITE.

- OBJECTIVES:
1. CLIENT WILL UNDERSTAND THE SELECTIVE USE OF THE TEST.
 2. CLIENT WILL UNDERSTAND WHAT A (+) OR (-) TEST RESULT MEANS.
 3. CLIENT WILL UNDERSTAND HOW THE AIDS VIRUS ACTS ON THE IMMUNE SYSTEM.
 4. CLIENT WILL UNDERSTAND THE CONCEPT OF RISK GROUPS.
 5. CLIENT WILL UNDERSTAND THE CONCEPTS AND MEANS OF AIDS RISK REDUCTION (IE. SAFE SEX GUIDELINES).
 6. CLIENT WILL UNDERSTAND THE CONCEPT OF RELATIVE RISK IN RELATION TO THE ACCURACY OF THE TEST.
 7. CLIENT WILL UNDERSTAND THE 2 WEEK - 6 MONTH TIME FRAME FOR POSSIBLE SEROCONVERSION AFTER EXPOSURE TO THE AIDS VIRUS.
 8. CLIENT WILL EXAMINE HOW HE/SHE HANDLES (OR HAS HANDLED) STRESSFUL SITUATIONS, SUCH AS A POSITIVE ELISA TEST RESULT.
 9. CLIENT WILL UNDERSTAND THAT THIS TESTING PROGRAM IS COMPLETELY VOLUNTARY AND ANONYMOUS, AND THAT A CLIENT IS FREE TO LEAVE AT ANY TIME.

Prototype Format
-For-
Providing Pretesting Information About
HTLV-III Antibody Testing

I. Introduction

- A. Introduce yourself and your professional role.
- B. Define the purpose of the session.
- C. Explain and emphasize the confidential nature of the discussion.

II. Information About The Test

- A. Assess the person's knowledge about the test by asking, "What do you know about the test?" followed by, "What would a positive test mean for you?" and "What would a negative test mean for you?"
- B. Supplement or clarify any information that is incomplete or incorrect, by presenting the following information:
 - o The primary purpose of this test is to screen donated blood and plasma. Blood or plasma which tests positive for antibodies to the virus will be discarded. Transfusions will be made safer by not using this contaminated blood.
 - o This test is for antibodies to the virus which causes AIDS - it does not, by itself, determine whether the person has AIDS.
 - o A positive test usually indicates past or present infection with the virus. Most people with a positive test will not develop AIDS within the next few years. Some people will have false positive tests.
 - o A person can obtain their test results by (insert local procedure).

III. Recommendations About Taking the Test

- A. Assess the risk status of the person by asking, "Why do you think this test would be useful for you?"
- B. If the person does not indicate that he/she may have been possibly exposed, tell him/her:
 - 1. Let's discuss some personal information so that we can best determine what this test might mean for you. This information about your medical and sexual history is confidential. First, hemophiliacs have special needs related to this test. Have you ever been treated for hemophilia. (If the person is a hemophiliac, explain that the test can only be performed after the person has consulted his or her personal physician or a comprehensive hemophilia treatment center.)
 - 2. Other people at increased risk of exposure to the virus are those who:
 - o are gay or bisexual males.
 - o inject drugs such as cocaine or heroin.
 - o have received blood transfusions.
 - o have immigrated to the United States since 1977 from countries with a high incidence of AIDS.

- o have symptoms consistent with AIDS or AIDS-related complex (ARC) such as persistent diarrhea, weight loss, or lymphadenopathy.
 - o are sex partners of people in any of the above groups, or sex partners of people with AIDS or positive HTLV-III antibody tests.
- C. Ask the person, "Based on this additional information, why do you think you may have been exposed?"
- D. Tell the person that at the present time, this test is not recommended for anyone except to test research project participants and donated blood. Provide the appropriate information depending on the risk status as follows:

1. People with no history of possible exposure or symptoms (low risk)

- a. People in this group should not be encouraged to have the test at this time since the meaning of a positive test has not been determined, nor has the proportion of false positive tests been determined.
- b. A positive antibody test can have a significant psychological impact on both the person tested and those who are close to him or her.

2. People with a history of possible exposure or symptoms (high risk)

- a. A positive test probably indicates infection with HTLV-III and the ability to transmit it.
- b. A small percentage of people who have a negative antibody test will be infected and able to transmit the virus.
- c. A positive antibody test can have a significant psychological impact on both the person tested and those who are close to him or her. At present, the prognosis for people who are infected with the HTLV-III virus is unknown. There is no treatment for HTLV-III infection.
- d. It has been suggested by some individuals that insurance companies or employers may seek information about positive test results as a condition of coverage or employment.

IV. Prevention Recommendations for People with a History of Possible Exposure or Symptoms

Discuss the following recommendations. Begin by asking, "What do you think you could do to avoid getting the virus or passing it to others?"

- A. Refrain from donating blood, plasma, body organs, other tissue, and sperm.
- B. When engaging in sexual activities, avoid passing or receiving body fluids, particularly blood, semen, saliva, feces, or urine. Use condoms.
- C. Reduce the number of sex partners, even if "safe" sexual activities are involved, to further decrease the chances of exposure.
- D. Avoid sex with people who have AIDS or may be infected with HTLV-III.
- E. Avoid sharing needles to prevent the transfer of the virus from person to person.

V. Conclusion

- A. Address any questions which the person has.
- B. Provide a handout to people with a history of possible exposure or symptoms which reinforces the prevention recommendations.

"SOMEONE WHO" EXERCISE

Each person has an identical exercise worksheet. Ask the other people in the group the questions on your worksheet, in any order that you choose, until you find "someone who" says "yes" to a given question. Have that person initial your worksheet beside that question, and then proceed to question another member of the group. Do not continue to ask questions of the same person who has signed your form, or ask other questions that have been initialled by someone, e.g., one set of initials per question.

ARE YOU SOMEONE WHO:

INITIALS

- | | |
|---|-------|
| 1. Is uncomfortable discussing sex-related issues with the opposite sex | _____ |
| 2. Considers anal intercourse to be abnormal | _____ |
| 3. Knows what "frottage" is | _____ |
| 4. Can comfortably ask a patient/client if they give "blow jobs" | _____ |
| 5. Has recommended masturbation to a patient/client | _____ |
| 6. Has gone skinnydipping | _____ |
| 7. Has had a sexual experience which you wish had not occurred | _____ |
| 8. Has been sexually excited by a patient/client | _____ |
| 9. Invites both gay and straight couples to parties | _____ |
| 10. Has ever thought that you might have an STD | _____ |
| 11. Has used a condom | _____ |
| 12. Has ever lied about a sexual experience | _____ |
| 13. Believes "rimming" is an abnormal sex practice | _____ |
| 14. Has ever had a sex partner discuss STD concerns with you | _____ |
| 15. Knows what "water sports" means | _____ |
| 16. Has discussed sex with your children | _____ |
| 17. Has described anal sex to someone else | _____ |
| 18. Likes your body | _____ |
| 19. Has been to a gay bar | _____ |
| 20. Has lied while doing this exercise | _____ |

(1895s)

4/17/85

OUTLINE OF HEALTH EDUCATION SESSION

1. CHECK IN
 - GREETING
 - CHECK APPOINTMENTS (SHOWS, NO-SHOWS, ETC)
 - MOVE TO HEALTH ED AREA
2. INTRODUCTION
 - BLUE PAMPHLET TO EACH CLIENT
 - REVIEW TONITE'S SCHEDULE (40 - 60 MINUTES, STATIONS 1 - 3)
 - PURPOSE OF HEALTH EDUCATION:
 - TO INFORM ABOUT THE TEST AND ITS MEANING
 - TO CONSIDER PERSONAL VALUE & REACTIONS
 - TO PROMOTE A RESPONSIBLE DECISION
 - TO ANSWER CLIENT QUESTIONS
 - SETTING A RETURN APPOINTMENT (SHOW APPT. CARD)
 - GETTING BLOOD DRAWN (SHOW VIAL -- 1/2 FULL)
 - REMIND CLIENTS THAT THEY ARE NOT OBLIGATED TO TAKE THE TEST --- THEY ARE FREE TO LEAVE AT ANY TIME.
3. DEMOGRAPHIC FORM
 - STATE REQUIRES INFO ABOUT USERS OF THIS SERVICE
 - FORM IS OPTIONAL AND ANONYMOUS
 - APPTMNT. CLERK WILL COLLECT (PLEASE RETURN PENCILS!)
4. VIDEO INTRODUCTION
 - THIS IS NOT A TEST FOR AIDS
 - THIS IS NOT A TEST FOR ARCS
 - THIS IS NOT A TEST FOR THE AIDS VIRUS
 - CANNOT BE USED TO PREDICT AIDS
 - CANNOT BE USED TO PREDICT ARCS
 - A POSITIVE TEST WILL TELL YOU IF YOU HAVE ANTIBODIES TO THE AIDS VIRUS
 - THIS MEANS YOU HAVE BEEN INFECTED WITH THE VIRUS SOMETIME IN THE PAST, AND YOUR BODY HAS RESPONDED BY FORMING ANTIBODIES.
 - STUDIES INDICATE THAT MANY PEOPLE WITH A POSITIVE ANTIBODY TEST ALSO HAVE THE AIDS VIRUS, AND ARE CONSIDERED CAPABLE OF TRANSMITTING THE VIRUS TO OTHERS
5. VIDEO

6. SAFE SEX CARDS: TO EMPHASIZE THE PRINCIPLES OF PREVENTION

- PASS OUT AS VIDEO CREDITS ARE STILL RUNNING (LOWER VOLUME)
- USE CARDS TO REINFORCE THE IDEA THAT WITHOUT A VACCINE OR WONDER DRUG, WE MUST RELY ON INDIVIDUAL BEHAVIOR CHANGE TO DEAL WITH THE AIDS CRISIS:

3 THINGS YOU CAN DO:

- DO NOT SHARE NEEDLES IF YOU USE IV DRUGS
- FOLLOW SAFE SEX GUIDELINES TO PROTECT YOURSELF AND YOUR SEXUAL PARTNER(S)
- KEEP YOUR IMMUNE SYSTEM HEALTHY (DIET, REST, EXERCISE, REDUCE STRESS, ELIMINATE AGENTS KNOWN TO IMPAIR IMMUNE SYSTEM FUNCTIONING--ALCOHOL, TOBACCO, DRUGS)

7. CLIENT QUESTIONS:

- KEEP IT SIMPLE
- DON'T LET ONE PERSON DOMINATE
- DON'T TRAP YOURSELF WITH "FACTUAL" STATEMENTS BASED ON MINIMAL SCIENTIFIC DOCUMENTATION.
- TRY TO INVOLVE AS MANY CLIENTS AS POSSIBLE

8. CLOSURE:

- ANY FINAL QUESTIONS?
- "FOR THOSE WHO HAVE DECIDED TO TAKE THE TEST, FOLLOW ME TO STATION #2. ANYONE ELSE IS FREE TO LEAVE OR TO ASK ANY REMAINING QUESTIONS."

REMINDERS:

- FOR THOSE CLIENTS WHO ARE OBVIOUSLY ANXIOUS, THE COUNSELORS CAN HELP IN A CRISIS.
- DON'T FORGET TO REFER TO THE AIDS HEALTH PROJECT GROUPS ON STRESS REDUCTIONS, COPING, ETC. WHENEVER APPROPRIATE.

Prototype Format
-For-
Counseling People with Seronegative HTLV-III
Antibody Test Results

I. Introduction

- A. Introduce yourself and your professional role.
- B. Define the purpose of the session.
- C. Explain and emphasize the confidential nature of the discussion.

II. Assessment

- A. Inform the person of the test results.
- B. If the risk status of the person is unknown, assess the risk status by asking, "Why did you decide to have the test performed?"
- C. If the person does not indicate that he/she may have been possibly exposed, tell him/her:
 - 1. Let's discuss some personal information so that we can best determine what the test result may mean for you. This information about your medical and sexual history is confidential.
 - 2. People at increased risk of exposure to the virus are those who:
 - o are gay or bisexual males.
 - o inject drugs such as cocaine or heroin.
 - o have been treated for hemophilia.
 - o have received blood transfusions.
 - o have immigrated to the United States since 1977 from countries with a high incidence of AIDS.
 - o have symptoms consistent with AIDS or AIDS-related complex (ARC) such as persistent diarrhea, weight loss, or lymphadenopathy.
 - o are sex partners of any persons mentioned above, or sex partners of people with AIDS or positive HTLV-III antibody tests.
- D. Ask the person, "Based on this information, do you believe that you have been exposed to the virus?"

III. Information About The Test

- A. Assess the person's understanding of the test result by asking, "Now that you know your test is negative, what does this test result mean for you?"
- B. Explain that this is a test for antibodies to the virus which causes AIDS.
- C. People with a history of possible exposure or symptoms (high risk)
A small percentage of people who have a negative antibody test will be infected and able to transmit the virus.
- D. People with no history of possible exposure or symptoms (low risk)
A negative test almost always means that the person is not infected with the HTLV-III virus.

IV. Prevention Recommendations for People With a History of Possible Exposure or Symptoms

Discuss the following recommendations. Begin by asking, "What do you think you can do to avoid infection with the virus?"

- A. Refrain from donating blood, plasma, body organs, other tissue, and sperm.
- B. When engaging in sexual activities, avoid passing or receiving body fluids, particularly blood, semen, saliva, feces, or urine. Use condoms.
- C. Reduce the number of sex partners, even if "safe" sexual activities are involved, to further decrease the chances of exposure.
- D. Avoid sex with people who have AIDS or may be infected with HTLV-III.
- E. Avoid sharing needles to prevent the transfer of the virus from person to person.

V. Conclusion

- A. Address any questions which the person has.
- B. Provide a handout to people with a history of possible exposure or symptoms which reinforces the prevention recommendations.

**WORKING GROUP ON
TESTING/COUNSELING/SUPPORT
COMMUNICATION #2**

To: Members of the Working Group

From: Rich Keeling, Group Manager

Date: December 1, 1985

Method: Federal Express

Statement on Testing: I have drafted, and enclose for your perusal and suggestions, a statement on HTLV-III antibody testing. This is one of the documents that our group will likely produce for the combined mailing around the first of the year. In addition to this one, we will need to come up with one on Counseling and Support.

In writing this draft, I have tried to incorporate the comments I had in advance from several of you. The enclosed document therefore reflects a combined perspective, and one which I think is fair. It suggests some relatively stringent guidelines for counseling pre- and post-test, and my own personal experience in working with people who wish to be tested certainly makes me feel that the need for such counseling must be one of our most important messages. The difficulties created by "knee-jerk" testing, testing without consent, and testing without an adequate discussion of such issues as record-keeping are enormous.

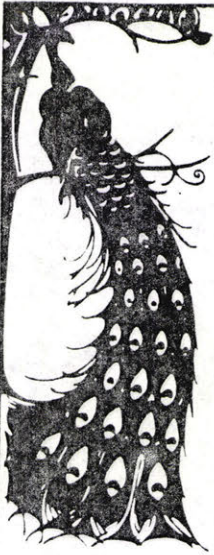
Please read through this, noting suggestions for improvements, and return it to me ASAP. I will be seeing two of you (Nancy, Lee) at the Berkeley meeting next Tuesday; it would really help to have comments back from Sue, Wayne, and Rich before I leave late in the day on Monday, December 9.

Statement on Counseling/Support: Wayne and I have talked about the need for materials which address the tough non-medical issues faced by gay people during the AIDS crisis. There are, of course, things published about "coming out," dealing with parents, and handling the stress of facing your sexuality; there are others things around which address what homosexuality is and isn't, addressed to the gay man himself, his parents, or others. I'm not certain that any of those materials are "adequate" in the current climate, and I wonder what we should do about that. One immediate answer is that we should see what already exists and assess it; so: please look around, see what you can find, and send it on to me so we can distribute it. Think, also, about what we can do if there aren't good materials.

Wish me luck: next Monday I embark on the 1985 approach to Marco Polo's travels. If the commuter airlines, US Air, the weather, and the Pittsburgh airport all cooperate, I will make it to San Francisco/Berkeley on Monday night (12/9); we will meet at Berkeley (great group coming -- in addition to Lee and Nancy, we'll have Paul Walters, Cathy Kodama, Mary O'Donnell, Joy Greenway) on Tuesday, 12/10. That night, on to St. Louis, where I'll meet on Wednesday 12/11 with Bob Wirag, Gary North. Then to Washington for a Public

Health Service Advisory Committee meeting on Thursday. Four calling birds, three French hens, two turtle doves, and...

Looking forward to hearing back from all of you.



December 1, 1985

Dear Friends:

Attached is a copy of revised guidelines for the NEA (National Education Association). These are based upon their guidelines, our guidelines and a two-day training I did for their National Urban staff, in November.

I would appreciate your comments and support, and I will be forwarding these guidelines to National staff on December 9th.

Thank you for your support and best wishes for the holiday.

Sincerely,

Jeremy
Jeremy Landau
Project Coordinator
Pacific Center AIDS Project

12/5

Mary,
Do you have
any ~~comment~~ comment
on the enclosed?

Jim

THE PACIFIC CENTER
FOR HUMAN GROWTH

POST OFFICE BOX 908 — BERKELEY, CALIFORNIA 94701 — TELEPHONE (415) 548-8283

Revised NEA Recommended Guidelines

Every school district, college and university should establish guidelines for dealing with AIDS. The recognized employee organization should review these guidelines and any dispute as to their meaning or application should be subject to appropriate grievance/arbitration procedures. The guidelines should be reviewed periodically and revised as necessary to reflect new medical information regarding AIDS.

Being aware of the fears and hysteria surrounding the AIDS epidemic and, on the basis of presently available medical information, we recommend the following guidelines:

1. Some infected students may potentially pose more of a risk to others. Students who lack control of their bodily secretions or who display antisocial behavior (such as biting) and those students with other medical conditions (such as weeping lesions) require a more restricted environment until more is known about transmission of the virus under these conditions. For infected students with questionable behavior or other medical conditions, individual judgements need to be made on a case-by-case basis, regarding placing these students in an unrestricted school setting.
2. The recommendation of whether an infected student shall be permitted to attend classes or participate in school activities with other students shall be made on a case-by-case basis by a team composed of public health personnel, the student's physician, the student's parents or guardian, and appropriate school personnel, which shall include the student's primary teacher(s). In making this recommendation, the team shall consider: (1) the behavior, development, and physical condition of the student; (2) the expected type of interaction with others in the school setting.
3. The recommendation of whether an infected employee should be permitted to remain employed in a capacity that involves contact with students or other school employees shall be made on a case-by-case basis with a team composed of public health personnel, the school employee's physician, the school employee and/or his/her representative, and appropriate school personnel. In making this recommendation, the team shall consider: (1) the physical condition of the school employee; (2) the expected type of interaction with others in the school setting.
4. The sexual orientation of a student or school employee shall not constitute reasonable cause to believe that he or she is an infected individual. No student, school employee or potential school employee shall be required to provide information as to his or her sexual orientation.
5. If an infected student in grades K through 12 is not permitted to attend classes or participate in school activities with other students, the school employer shall make every reasonable effort to provide said student with an adequate alternative education. To the extent that this requires personal contact between the student and school employees, only those school employees who volunteer shall be utilized. If needed, the school will assume liability for private tutoring.

6. If the employment of an infected school employee is discontinued, said school employees shall be entitled to use any available medical leave and receive any available medical disability benefits as we seek to continue health insurance and to provide retirement and disability benefits.
7. A school employee shall not be required to teach or provide other personal contact services to an infected student or to work with an infected school employee, unless a determination has been made pursuant to the above to permit said individual to remain in the school setting.
8. NEA and its affiliates shall provide appropriate intervention where any items in this policy have been violated.
9. The identity of an infected individual or an individual who there is reasonable cause to believe is an infected individual shall not be publicly revealed.

American College Health Association
Task Force on the Acquired Immunodeficiency Syndrome (AIDS)
Statement on HTLV-III Antibody Testing
December, 1985

The American College Health Association recognizes that there are important limitations to the clinical application of the currently available enzyme-linked immunosorbent assay (ELISA) test for antibodies to human T-lymphotropic virus, type III (HTLV-III), the agent thought to cause the Acquired Immunodeficiency Syndrome (AIDS). These include:

1. The occurrence of false positive tests in a small but significant percentage of people whose blood does not in fact contain antibodies to HTLV-III and who are not infected with the organism. Some of these people have cross-reacting antibodies; in other circumstances, technical problems cause the test to be falsely positive. These people have negative confirmatory tests done by the western blot method. Some technical problems are specific to individual test kits and procedures.
2. The rare presence of false negative tests in some people who actually have been infected by HTLV-III, and whose blood does in fact contain antibody.
3. The occurrence of negative tests in people who are in fact infected, but whose antibody response has not yet occurred; this situation is encountered in the first 6-8 weeks after infection.
4. The occasional existence of negative tests in some people who are infected with HTLV-III and may even have symptomatic immune deficiency and recoverable virus in blood and body fluids.
5. The need for confirmation of positive results by a more specific procedure, the western blot test.
6. The absence of any specific clinical correlates to a positive test result. People with confirmed positive tests may have:
 - a. Asymptomatic infection, currently marked only by a positive antibody test. Most of these people are contagious (infectious); some are not. Some may progress to have AIDS-related complex (ARC) or AIDS itself, and others will stay

healthy for years. No feature of the ELISA or Western Blot test distinguishes among these possibilities.

b. Thrombocytopenia (low platelet count) with or without evidence of a hemostatic defect (tendency to bruise or bleed easily). Some of these people will progress to develop ARC or AIDS; others will stay clinically stable for long periods of time.

c. AIDS-Related Complex (ARC). Some of these people will progress to have AIDS itself; some will regress to an asymptomatic state. Many appear to remain clinically stable for long periods. Again, no feature of the ELISA or Western Blot test distinguishes among these possible outcomes.

d. Full-Blown AIDS manifest by major opportunistic infection; premature, unusual cancers, or both.

7. The tendency of many people to misinterpret the test and misunderstand its results. A positive test result is commonly misapprehended as evidence of the existence of AIDS itself or of the inevitability of development of AIDS. In some contexts, a positive test has been interpreted as evidence of homosexuality or drug abuse. Positive test results, whether or not they are confirmed, have been regarded as reason for termination of employment, refusal of insurance coverage, and exclusion from school.

8. The fact that the ELISA test, when applied as a screening device to a population in which the prevalence of HTLV-III infection is low, becomes significantly less reliable in correctly identifying seropositive people (those with HTLV-III antibodies). Such populations include, for example, unselected entering college and university students, health sciences students, and institutional employees.

9. The fact that the advice, counsel, and instructions given to people in high risk groups for AIDS are similar, whether or not testing is done; that is, that a positive test does not materially change the counsel provided, though it may certainly confirm suspicious and elevate anxiety. Whether or not they are tested, people in high risk groups must not engage in any activities which could transmit AIDS.

The American College Health Association further recognizes that the tests for antibody to HTLV-III were developed as procedures to screen donated blood, and it wholeheartedly supports their utilization for that purpose. ACHA encourages all citizens to abide by the request of the American Red Cross and

the Public Health Service that persons in certain defined high risk groups voluntarily exclude themselves as blood donors. Those groups include:

1. Anyone who demonstrates the signs or symptoms of AIDS.
2. Males who have had sex with more than one male since 1978.
3. Males whose male sexual partner has had sex with more than one male since 1978.
4. Past or present abusers of intravenous drugs.
5. Hemophiliacs.
6. Sexual partners (male and female) of persons in these groups.

Under no circumstances should individuals use blood donation as a way to be tested for HTLV-III antibodies, however. The occurrence of even a small percentage of false negative tests and the existence of infectious virus in people who have been quite recently infected and still have no serum antibody demand that individuals in risk groups not even attempt to give blood.

Despite the limitations of the tests, they may provide important, useful information in certain circumstances. Given the likelihood that people with positive tests are infectious, a positive test may provide greater motivation for alterations in behavior than the simple possibility or probability of infection as assessed by a patient and his/her health care provider. In certain clinical circumstances, the test is an important adjunct to the evaluation of an illness, especially when the symptoms and signs may suggest AIDS or an AIDS-related disorder. Some people are so worried about possible exposure to HTLV-III that the concern itself becomes a distraction, a stressor, and a limitation to their function; assuming that the potential exposure occurred at least 2-3 months prior to the intended time of testing, the test may relieve anxiety, if negative, or bring more useful counseling approaches if confirmed positive. Those involved in a new relationship may desire testing to protect the health of both partners; in certain circumstances, the test, performed on both partners, may be helpful. Women in high risk groups who are or intend to become pregnant may wish testing in order to avoid perinatal transmission to offspring.

In most jurisdictions, only cases of AIDS meeting the criteria of the revised surveillance definition of the Centers for Disease Control (see MMWR 1985; 34:373-375) are reportable

to local health authorities. There are, however, some (Colorado) in which the fact of a positive HTLV-III antibody test, with or without evidence of ARC or AIDS must be reported. In some areas, such reports must include information about the sexual preference of the person whose results are reported.

Even where test results are not reportable by law, they commonly become part of the medical record to the person tested. Such information is protected from disclosure without consent of the tested individual by a number of statutes, and thus is "confidential." However, access to the information may be secured by potential employers, insurers, and others who produce an authorization signed by the person tested. The results then become open to the interpretation of the agency or individual securing consent for their release.

Truly anonymous testing is available in certain areas. In these testing programs, no disclosure of the name of the individual tested needs be made, and no named record is generated. Thus, no untoward consequences of accidental or malicious compromise of confidential data can occur.

USING THESE FACTS AND OBSERVATIONS, THE AMERICAN COLLEGE HEALTH ASSOCIATION MAKES THE FOLLOWING RECOMMENDATIONS IN REGARD TO TESTING FOR ANTIBODY TO HTLV-III:

1. The American College Health Association recommends that any individual so requesting be provided accurate, timely information on which he or she can base a rational, personal decision about taking the HTLV-III antibody test. The issues involved in such decisions are too complex and personal to allow for blanket recommendations that any group should or should not be tested.

2. Those who counsel or advise students or employees about HTLV-III antibody testing must themselves be thoroughly familiar with the medical, psychological, and social implications and the technical limitations of the tests.

3. College and university health officers should be aware of the procedures and qualifications of local and regional sources of testing for HTLV-III antibody.

4. No student or employee should be tested, or referred for testing, for HTLV-III antibody unless: the testing is confidential or anonymous, positive results are confirmed by specific testing, counseling is provided, and informed consent is obtained.

5. All persons desiring HTLV-III antibody tests require counseling both before and after the tests are done. No

one should have the test done unless pre-test counseling has been provided; no one should be given test results without the ready availability of post-test counseling. If such counseling is not available within the institution, there must be arrangements for it to be provided elsewhere.

6. Test results should never be provided by telephone, both to guarantee confidentiality and to facilitate post-test counseling.

7. Care providers must be aware that a variety of psychological reactions to either confirmed positive or negative test results can be expected. It is impossible to overstate the importance of sound knowledge, a non-judgmental approach, and a compassionate, unhurried attitude on the part of the care provider.

8. Adequate pre-test and post-test counseling require:

- a. the allotment of sufficient time
- b. a private setting
- c. guaranteed confidentiality
- d. encouragement to the patient to ask questions, state fears, and verbalize reactions
- e. the availability of follow-up counseling, when appropriate and indicated

9. Information provided during counseling sessions should include:

- a. the technical and clinical capabilities and limitations of the test, and its cost
- b. the significance of positive and negative results
- c. the local procedures for handling confidential medical information
- d. the range of psychological impact and reaction to the test
- e. alternatives to testing: behavior modification without testing
- f. the best current information about the transmission of AIDS; behavioral guidelines

for avoiding transmission

- g. the possibility that confusing or conflicting information will be presented by other sources, especially the media
- h. resources for further information
- i. arrangements for local medical and psychological follow-up

10. The disposition and handling of test results and other confidential information are addressed in a separate document written by the ACHA Task Force on AIDS. Briefly, this information is protected by statutory standards; unauthorized disclosure to anyone creates liability. Whether the counseling sessions, the fact that the test was done, or the test results themselves should be recorded in the medical record are difficult issues. ACHA suggests that, given the potential for misuse of this information, care providers weigh carefully the importance of entering such records, except in circumstances of the medical evaluation of specific symptoms and/or signs suggesting HTLV-III infection. At the very least, patients must be informed in advance about exactly what information will be entered in the medical record and might therefore be available to others.

11. The American College Health Association strongly discovers the use of any test for HTLV-III antibodies as a mandatory "screening" procedure in any setting except blood donation. Especially, there should be no screening of:

- a. entering students, before or after admission
- b. any group of current students or employees
- c. those identified by supposition as being at high risk
- d. health sciences students
- e. food service employees, whether students or not

12. All health care providers should be aware that test procedures, interpretations, and reporting requirements may change over time; it is important to be familiar with current information and to stay in touch with developments in the field.

AIDS Health Project

WHAT DOES THIS TEST MEAN FOR YOU?

A Report on the Counseling Protocol

Implemented by the U.C.S.F. AIDS Health Project

at Alternative Test Sites

AIDS Health Project

by: Norman Spencer, Ph.D. - Program Analyst - U.C.S.F. AIDS Health Project

The decision to take the test for antibodies to the AIDS virus is a complex issue for Gay and bisexual men in San Francisco. How test results with potentially life threatening consequences are heard, interpreted and acted upon, is a complex psychological and cultural process even without the social stigma surrounding homosexuality and AIDS. This article describes the development and implementation of a counseling program offered to participants in a Centers for Disease Control and the San Francisco Department of Public Health sponsored "Alternative Test Site Program". Statements made by program participants suggest that the process of confronting information, no matter what the result, is a strong catalyst for major shifts in personal and social values. These changes tend to be in the direction of adoption of safer sexual practices, decreased number of multiple sexual partners, and more long-lasting monogamous relationships.

AIDS Health Project

Medical Anthropology and the AIDS Epidemic A Case Study in San Francisco

by: Norman Spencer, Ph.D. - Program Analyst - U.C.S.F. AIDS Health Project

INTRODUCTION:

An epidemic of a "new" disease, like AIDS, is dramatically influenced by sociocultural factors. These factors have been shown to have a crucial influence on the ability of health professionals to effectively manage the epidemic disease. Rosenstock, et al (1960), showed that prompt, rational responses to the threat of epidemic flu in 1957 were compromised by jurisdictional disputes, communication failures effecting deployment of resources and other economic and political factors characterizing the health delivery institutions of urban America. In San Francisco, efforts to control the AIDS epidemic have frequently generated complex confrontations between various social factions and political or social institutions, e.g., the issue of closing bath houses.

THE AIDS EPIDEMIC:

Susan Sontag has observed that "any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally contagious" (Sontag '78:6). She also cautions that such social attitudes about illness kindle the flames of self doubt and self blame unavoidably associated with catastrophic illness.

But AIDS is not only mysterious, it is contagious, it is deadly, and it is already associated with highly stigmatized members of society, i.e., IV drug users and homosexual men. The AIDS epidemic involves society in a crisis which reaches beyond even the complexity of technical and emotional issues which usually accompany disaster. How can society be expected to respond when the stigma of a deadly contagious disease is added to a "spoiled identity" (Goffman'63)?

In San Francisco the AIDS epidemic is a social drama which continues to unfold in the political and historical framework of "Gay Liberation". It is estimated that approximately 25% of San Francisco's adult male population are self-identified as having a sexual preference for other men. (Research & Decisions Corp. '84:21-22) It is further estimated that nearly 2/3 of these 70,000 men have come to San Francisco in the last ten years. In the wake of the sexual liberation and social tolerance which identified San Francisco in the 1960's and early 1970's, the City has become a center of Gay activism, and gay lifestyles. The gay population is sufficiently concentrated to form several distinct neighborhoods in San Francisco (Research & Decision Corp. '84:18-19). Within the gay population, these neighborhoods are somewhat stereotyped. Both lifestyle and preference for certain kinds of sexual experience form meaningful distinctions between neighborhoods: the "leather" bars South of Market as contrasted with the "drag" element of the Tenderloin district. Added to the brew of

cultural complexity presented in the AIDS crisis is the fact that San Francisco is a city of highly distinct neighborhoods both ethnic and social in character: the Old Chinatown of Grant and Stockton Streets, and the New Chinatown of Clement Street; North Beach is both Little Italy and the bastion of Kerouac's "Beat Generation"; the largely black Western Addition is not far over the hill from the "old wealth of Pacific Heights and the yuppie environs of Union Street and, at least since the 1960's, the Haight represents a cocophany of socially "marginal men" and women.

Late in 1984 a blood test for antibodies to the AIDS virus was licensed by the F.D.A. The primary purpose of the test was to safeguard the nation's blood supply. The test would prevent the transmission of the AIDS virus to transfusion recipients and others using products made from whole blood or plasma.

With the F.D.A. announcement, a loud, political cry was heard from Gay organizations and activists who saw in the test a mechanism which would foster discriminatory practices against those shown to be reactive to the antibody test. The test was seen as the instrument of a 20th-century witch hunt. Ironically, the blood banks feared an onslaught of "high-risk" donors who would maximize the cost of a unit of blood, since large numbers of donations would need to be discarded, and increase the chance of a failure to detect an infectious donation. Virtually every major Gay organization, including those organized in recent years specifically around the AIDS epidemic, came out against the test. To legal issues of insurance, employment, housing discrimination and the threat of quarantine were added medical injunctions that the test was of no medical value since it was not diagnostic of AIDS or an AIDS related condition (ARC).

A survey done in San Francisco in November of 1984 revealed that some 69% of Gay men in the sample said they would take the test if it was available, other than at the blood bank. By May of 1985 only 17% indicated they would take the test (McKusick, Coates, Horstman, '85:8). Largely in response to the demands of the blood banks, who would screen all blood with this test, the C.D.C. made funds available for state and local governments to set up a time limited program of alternative test sites.

In response to the request for proposals put out by the Centers for Disease Control in February of this year (1985), Mr. Gary Titus and Mr. Jeff Amory of the San Francisco D.P.H. "AIDS Activity Office" developed a plan for an Alternative Test Site Program in San Francisco which coordinated resources of the City and existing contract service agencies. In particular, their proposal gave the task of public relations and community education regarding the AIDS Antibody Test and the Alternative Test Site Program to the San Francisco AIDS Foundation. The system of appointments, health education about the test for interested individuals, the actual blood drawing, and testing would be handled directly by the Department of Public Health. The need for more in-depth counselling and referral services around the revelation of the test result suggested the AIDS Health Project as the contract agency with the specialized resources to quickly develop such a protocol.

As part of a research program dating back to 1978, San Francisco's City Clinic had been giving out test results for almost two months prior to the opening of the Alternative Test Sites. This experience was useful in designing the Alternative Test Site protocol. In addition, the experience and earlier work done by psycho-social researchers and clinicians at the University of California San Francisco was also readily available (T. Coates, L. Temoshok, J. Moulton). The Centers for Disease Control provided its most recent training materials including videotaped role-playing of test result presentations.

The breadth of political, medical, and moral issues which all come to bear importantly in this social drama are beyond the scope of this paper. The primary goal of this article is to describe the counseling protocol used in the presentation of AIDS antibody test results. The pre-test health education program will also be described.

The San Francisco AIDS Foundation produced a brochure, a special videotape on the test, newspaper ads, press releases and public forums. All stressed the importance of informed choice based on the best available facts in making the decision to take or not take the test. The videotape set the framework for considering the test, and provided an overview of relevant medical, legal, and psycho-social factors. The information is presented as a list of considerations for and against the test option. In this way participants make their own estimation of the costs and benefits of the test relative to their particular situation. Participants are encouraged to take a hard look at what their reaction might be to either a positive or negative antibody test result. It is suggested that they recall how they have reacted to other stressful situations. Participants are also asked to consider health positive steps they can take if they are negative as well as if they are positive for the AIDS Antibody. Finally, participants are asked how knowing their antibody status might influence their health related behaviors. These questions are brought up in a small group setting (usually four to six participants) after viewing the AIDS Foundation videotape.

The Health Educator makes it clear to participants that they are free to leave at any point up to the collection of their blood sample. Additionally, they may decide during the two weeks between blood drawing and results that they do not want to know the result. Participants can simply not show up for the test results. Health Educators make it clear that a person should take all the time they need to make their own decision, and that a new test can be scheduled at a later time - the full, anonymous process can be re-initiated at the participant's discretion.

EARLY EXPERIENCES AT THE TEST SITES:

The first people to seek out the test through this program were highly informed. Most were risk group identified and many were themselves health care providers. An initial high rate of response to the program soon tapered off and then slowly began to re-build. By the first week of August - after a full month of operation, the clientele of the program appeared to be a representative sample of the "at-risk" population in San Francisco. Most participants continue to be

homosexual and bisexual men.

As of October 18, 1985, 3772 participants had taken the test. These early participants reveal a realistic attitude regarding risk. The vast majority identified realistic risk and the desire to clarify the fact or falsity of presumed exposure and infection. 70% of the men in this group and 99% of the women had no serologic evidence of infection with the AIDS virus.

While the motivations for seeking the test are variable, the protocol used in presenting test results has remained essentially the same. The protocol was designed to work with the participant on three primary dimensions. First, the participants' perceived risk, i.e., expectation of a positive or negative antibody finding. This dimension also involves, the accuracy of that perception, or knowledge of AIDS including the implications of a positive or negative antibody test (perceived risk and expectation). The second dimension involves the participants' psychological readiness to deal with the result as indicated by history, statements of expected response to a positive or negative result, e.g., health plans, fear of binge behavior, etc., and the participant's presentation in the session, e.g., statements indicating level of anxiety, withdrawal, denial, etc. (coping readiness). The third dimension incorporates the participants' immediate reaction, and statements about the future. The counselor encourages the development of a health plan along with strategies to deal with feelings and behaviors which might be self-defeating (behavior/health plan).

To implement the test protocol, the counselor works with the participant to set an agreed upon structure for the session from the outset. Based on the premise that it is the participant's "right to know", it is important for the counselor to remain open to negotiation even given a specific agenda, i.e., the structure of the protocol must remain flexible to the needs and even demands of the participants. In this regard, it can be imagined that after waiting for two weeks the participant will come to the "result" session with a relatively high level of anticipation and a desire to "get it over with." Experience has demonstrated that most clients are still quite willing to spend a few minutes developing a rapport with the counselor and to respond to queries about their risks and expectations when this structure is outlined as soon as the counselor introduces him/her-self:

Hello, my name is _____. I will be giving you your test results tonight and spending some time with you to talk about what, exactly, this test means and how you can use your test result to help maintain your health. The first thing I would like to do is deal with any questions you have about the test and get your own thoughts about how you plan to use the test result - whether positive or negative. Then we will look at your test results and talk about what they mean to you.

The participant's expectation is an important variable in how they respond to the test result. An evaluation of the accuracy of the participant's expectation and the actual outcome gives the counselor a means with which to direct the consultation. In this way, the result

session can be structured to minimize adverse or self-defeating reactions. The counselor is able to increase the accuracy of the participant's expectation and/or respond to psychological factors which may diminish or enhance the participant's acceptance of the test result.

Participants who have steeled themselves realistically for a positive antibody test and then receive a negative reading may be very open to suggestions to maintain their renewed sense of health. A strong, immediate, reinforcement accompanies the revelation that there is no sign of infection with the AIDS virus. The participants have rid themselves of a state of ill health they believed they had.

A contrasting example is provided by the individual who demonstrates a somewhat unrealistic expectation of having no evidence of antibody to the AIDS virus in spite of statements demonstrating a reasonable risk of exposure. If this person is in fact positive, the revelation is likely to be very upsetting. Here the counselor can anticipate considerable cognitive dissonance in the participant's attempts to integrate the test revelation into their lives. Such dissonance can be expected to resolve itself with the employment of classical defenses such as denial or even reaction formation. Being able to anticipate these potential responses helps the counselor to alert the participant to pitfalls. The counselor can stress the value of realistic steps to promote health which the participants can take. This strategy side-steps a sense of helplessness which may accompany confronting the evidence of infection with the AIDS virus. (See attached paradigm of participant expectations and outcomes.)

Revelation of the Test Result: Some Specific Guidelines

Some experts feel that participants will have little room to hear or process information after the result is presented. One participant actually came back to the health center the night following his appointment saying "I know we went over all this last night, but I need to ask some questions. I didn't hear a word the counselor said after "...Your results came back positive..."

However, the philosophy of this program stresses the individual's right to establish when they are told their results. Open dialogue allows participants to "take the lead" in determining how soon they get their test result without undermining the consult as a whole.

To help the counselor keep in mind the points deemed most crucial to the long term utility of test results a checklist has been devised (see appendix). A degree of disruption in the participants ability to attend and integrate information in this situation is reasonable to assume. To help participants recall and use information, hand-outs are provided. The hand-outs outline major points to be taken into account when deciding with whom the participant will share the result: Health Care professionals, lovers and other contacts who might be at-risk for past or future infection, and referral resources to deal with resulting health and personal issues.

The actual revelation of the test has proved to be most readily

accepted when delivered in a straight-forward manner, without affect, and without undue expression of concern. Some counselors find it useful to refer to the test result itself as a series of numeric scores explaining, for example: "Your ELISA test shows that you were positive on three consecutive tests."

Once the result is delivered, the counselor should resist the temptation to fill the silence, but wait for the participant to respond. [The participant's reaction has shown itself to be highly predictable based on his/her perceived risks and expectation.]

Up to this point the discussion has centered around factors affecting how test information will be processed and integrated into the participants life. These factors include: perceived risk of exposure, expected test outcome, and anticipated responses to either a positive or negative antibody finding. The counselor makes use of these factors in shaping his or her presentation so that the participant is most able to hear the information and draw upon his or her own stated structure of attitudes and motivations to best deal with the medical and psychosocial implications of the test. Both cognitive dissonance and emotional defenses suggested by the participants expectations and anticipated reactions guide the counselor's questions and suggestions.

In addition to these process considerations, several content areas must also be worked into the consult.

The content issues relate to the participant's "at-risk" behaviors, past and future. The information presented to the counselor about the participant's perceived risk points directly to the relevant areas of behavior change to be considered.

The best possible use of the test result involves both content and process factors. The kind of formulation which can give the most supportive direction to participants must include the participant's internal strategies, medical knowledge, and finally their responses - emotional and behavioral. During the latter part of the consultation, after the presentation of the test result, the counselor allows participants to express their feelings freely. Emotional release has a cathartic value and tends to reveal fundamental beliefs and patterns of response operating in the participant. This is not to say that a counselor will encourage highly emotional responses. In fact, the session provides an opportunity for modeling of appropriate emotional release and return to here-and-now reality. The participants ability to react and then re-orient their social presentation in the context of the consult is important. For one thing, it gives a strong indication of their ability to absorb and later act on any "health planning" discussed in the session.

It is useful to deal fully with doubts or feelings of ambiguity or even confusion expressed by the participant before moving toward behavioral plans. In situations where detailed health planning would be premature, the counselor can utilize what he or she has learned about the participant to encourage them to continue toward a health promoting integration of the test result. For example, the obvious value of staying free of viral infection is a strong motivational suggestion,

particularly with individuals who expected a positive antibody test but in fact had no evidence of infection. Similarly, the punitive effects of future exposure can also be used with both serologically positive and negative participants. The counselor may point out that in 1980 the chances of a random encounter with the AIDS virus through unsafe sex with a homosexual or bisexual man was about like playing "Russian Roulette," i.e., about one in six. Playing the same game today is not the same. "Now, in San Francisco, the game of sexual exposure is played with a six-gun loaded with four shells instead of one."

To reduce any sense of uncertainty or helplessness and provide a psycho-social footing the counselors probe into what the participant can do. A question like: "What steps can you take to keep yourself healthy?" points in such a direction. Such a question will reveal unspoken fatalism which can then be dealt with in the open. This question tends to point toward potential solutions or adaptive actions on the part of the participant, e.g., nutrition, knowledge of safe sex, health planning strategies, etc. Even more importantly, it provides the participant with both an experience of renewed self-control (or efficacy) and a way of dealing with a problem which tends to maximize a person's sense of being able to effect their own fate. Another tactic is to ask participants - in light of their own past risk behaviors and their knowledge of their own psycho-social strengths and weaknesses - "What kinds of things are most likely to get in your way in following this health plan", or "these safe-behavior guidelines?" This tactic fosters both a realistic appraisal of strengths and weaknesses and provides the participant with an opportunity to consider and rehearse their most adaptive strategies...

Issues involving to whom and how to share test results are particularly important as ongoing medical, ethical and legal concerns. In addition to referring to the major points in both the San Francisco AIDS Foundation brochure "AIDS Antibody Testing" and the pre-test video, antibody positive participants are given a three page handout detailing the issues and arguments around telling others about their results and basic health precautions. In the counseling session, a great deal of productive work can be framed around the basic issues by asking: "What concerns would you have about contacting these people?"

Questions like those above are meant to open an ongoing process which points up issues of concern for the health of participants and the people with whom they interact. The structure sets in motion a process which emphasizes realistic problem solving and minimizes non-productive and even destructive responses. The counselling session prompts participants to confront salient issues of health promotion and prevention of virus transmission. It is then more difficult for participants to avoid dealing with the facts of the AIDS epidemic in relation to their own particular circumstance.

The "Integration phase" of the counseling session leads to a review of referral resources. The counselor can close the session with a presentation of resources directed to specific needs brought up by the participant in the consult. Follow-up resources and other health guidelines should also be made available in written form given the evidence that often little is absorbed by the participant after the

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result is presented.

Giving the participant "the real facts" as we know them is important. But in the context of this consultation protocol, strict "health education" is secondary to: (1.) the ethical principle of the participant's "right to know"; (2.) dealing with the individual's personal reactions - fear, sense of loss, sense of relief or renewed freedom; (3.) and well considered referral to resources in the community - which the participant may feel no need to utilize until some time after receiving the result of their AIDS antibody test.

THE COUNSELING EXPERIENCE:

In all societies...the issue of death throws into relief the most important cultural values by which people live their lives and evaluate their experience. Life becomes transparent against the background of death, and fundamental social and cultural issues are revealed. (Huntington & Metcalf, '79:2.)

Systematic interviews with the counselors in the Alternative Test Site Program have been initiated as part of the program evaluation process. A common observation in the counseling is that participants, whether receiving a positive or negative test finding are using the situation as a catalyst to re-examine their personal values and lifestyle. While there is a range of responses, in these re-interpretations most participants stress their desire to build stronger, more long-lasting personal relationships. The majority use the experience both as a catalyst to develop healthier modes of behavior and sources of satisfaction which are seen as ongoing and long term. Additionally, many state a greater attention to the pleasures of the moment derived from "just living" rather than seeking out hedonistic satisfaction. The shifts are almost invariably placed in the context of an ongoing lifestyle which includes greater self-acceptance - including sexual preference. The AIDS epidemic is not held as a reason to abandon homosexual preference. For Gay men this crisis is shifting what it means to be Gay. As related by participants in the Alternative Testing Program, this shift emphasizes that Gayness is a way of being in society rather than a euphemism for homosexuality. Participants describe dealing with the anxieties associated with the fear of developing AIDS, the fear of death. They also frequently refer to a growing sense of social responsibility as Gay or bisexual men.

In anticipation of ongoing problems in dealing with the gravity of this test result and in anticipation of not infrequent delayed reactions, a system of follow-up counseling has been provided. At the end of the result interview, all clients are offered a free follow-up visit with a specially trained counselor in private practice. A voucher for a specific therapist has been given to participants who could call for an appointment with that counselor for up to two weeks. A drop-in group for people who had received results was also set up. Experience in this setting demonstrated the need for short term follow-up and delayed reactions were frequently reported by participants.

SUMMARY

The basic aims of the result presentation interview continue to be: handling immediate reactions and behavioral concerns; developing as inclusive and long-range a plan as possible (given the participants initial reaction); and encouraging behavioral plans which decrease risk behaviors. To make both plans and resources more concrete, participants are given written material at the end of the session. This material covers: risk reduction (safe sex, drug use, infection control); major issues to consider before telling others about the test result; and consideration for potential fathers or mothers (vertical transmission of the AIDS virus).

The growing numbers of individuals seeking the antibody test at these "alternative test sites" attests to both an expressed demand for the test from the public sector, and the efficacy of the San Francisco Department of Public Health program. This success demonstrates the value of a program which is anonymous, offers no moralistic interpretations, and promotes pragmatic problem solving and health planning.

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TASK FORCE ON THE ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS)

General Statement on Institutional Response to AIDS

December 2, 1985

The recommendations and guidelines included in this Statement augment and extend those of the Preliminary Statement on Disease Transmission issued by the American College Health Association (ACHA) on September 25, 1985. They are based on the best currently available medical information and on recommendations of the Public Health Service and the Centers for Disease Control. As indicated herein, ACHA will make available more detailed guidelines and information in certain specific areas of concern to colleges and universities in a series of reports and statements to be released in the near future.

The American College Health Association acknowledges the valuable assistance of the American Council on Education in the development of guidelines pertaining to the legal issues and questions presented by AIDS.

The primary response of colleges and universities to the AIDS epidemic must be education. Because there is no specific therapy for AIDS or AIDS-related conditions, the most important goals for institutions will be those of increasing awareness and providing education to prevent further spread of the disease. The American College Health Association recommends that the organization and completion of effective educational programs about AIDS be an activity of the highest priority for all institutions of higher learning. Such programs must address not only undergraduate students, but also graduate and professional students; they must reach not only residential students, but also commuters. Educational programs about AIDS should also be available to students in junior and community colleges and in programs of continuing education. Furthermore, universities and colleges should provide AIDS education for institutional employees, faculty, and staff.

Such educational programs will address the major intervention currently possible in limiting the consequences of AIDS, which is *primary prevention*. They may also be of paramount importance in discharging the institution's responsibility to protect its student body and staff from the transmission of AIDS. Since the current medical evidence indicates that no actual safety risks are created in a normal academic or employment setting, the administration of effective AIDS education and training programs provides the best way for institutions to render enrollment or employment safe and healthful. The AIDS epidemic raises issues of liability that are of great concern to college and university administrators; the most effective means of addressing these issues at present is to educate students and employees about AIDS and to take reasonable precautions such as are suggested herein.

In order for educational programs to be effective, they must provide current information, use reliable, up-to-date materials, and be widely available. The Task Force on AIDS of the American College Health Association has revised the organization's educational brochure on AIDS and is distributing it to all institutions. Detailed recommendations for educational programming, including suggested formats and methodologies, will be forthcoming from the Task Force shortly.

The American College Health Association recommends that institutions not adopt blanket policies concerning students with AIDS or AIDS-related conditions. Instead, it suggests that certain guidelines be followed and that the institution analyze and respond to each case as required by its own particular facts. Recommended guidelines are included in this Statement and in subsequent statements by the Association. Colleges and universities will benefit from the maintenance of as much flexibility as possible in dealing with the issues AIDS raises; given the uncertain legal obligations and challenges involved, institutions are advised not to devise and implement detailed policies at this time. However, it seems appropriate for college and university officials to identify and designate a person, group, or department to assume a managerial role in providing consistent and reasonable analysis of each case.

Guidelines for institutions derive from the best currently available medical facts about AIDS.

Recommendations apply to all students or employees who are known to be infected with the virus thought to cause AIDS, Human T-Lymphotropic Virus, type III (HTLV-III); this includes those who have a condition meeting the surveillance definition of AIDS itself, those who have one of the lesser manifestations of infection (AIDS-Related Complex, or ARC), and those who are currently healthy but have evidence by the presence of a serum antibody to HTLV-III of exposure to and infection by the virus.

Current knowledge indicates that students or employees with AIDS, ARC, or a positive HTLV-III antibody test do not pose a health risk to other students or employees in an academic setting. AIDS is thought to be transmitted by intimate sexual contact or by exposure to contaminated blood. Although HTLV-III can be found in many body secretions of those who are infected, its presence there is not necessarily correlated with disease transmission by those fluids. There has been no confirmed case of transmission of AIDS by any household, school, or other casual contact. **The Public Health Service states that there is no risk created by living in the same house as an infected person; caring for an AIDS patient; eating food handled by an infected person; being coughed or sneezed upon by an infected person; casual kissing; or swimming in a pool with an infected person.**

These facts, derived from the best epidemiologic data currently available, are the basis for the following guidelines recommended by the American College Health Association.

1. Most college and university students who have AIDS, ARC, or a positive HTLV-III antibody test, whether they are symptomatic or not, should be allowed regular classroom attendance in an unrestricted manner as long as they are physically able to attend classes. See also Recommendation #12.
2. There is no medical justification for restricting the access of students with AIDS, ARC, or a positive HTLV-III antibody test to student unions, theatres, restaurants, cafeterias, snack bars, gymnasiums, swimming pools, recreational facilities, or other common areas. The ACHA is developing a statement that addresses such specific concerns as contact sports.
3. In the program of education that the institution provides, it should emphasize the following recommendations of the Public Health Service:
 - a. Even though they may be asymptomatic, persons with confirmed positive HTLV-III antibody tests may transmit infection to others through anal or vaginal sexual intercourse, the sharing of needles, and possibly, exposure to others through oral-genital contact or intimate kissing.
 - b. The efficacy of condoms in preventing infection with HTLV-III is unproven, but the consistent use of them may reduce transmission.
 - c. Toothbrushes, razors, and other implements that may become contaminated with blood should not be shared.
 - d. Persons with AIDS, ARC, or confirmed positive HTLV-III antibody tests should not donate blood, plasma, other body organs, other body tissues, or sperm. The American College Health Association also endorses the request of the American Red Cross that persons who fall into defined risk categories for AIDS not donate blood or plasma.
 - e. If persons with confirmed reactive (positive) antibody tests have accidents involving bleeding, contaminated surfaces should be cleaned with household bleach freshly diluted 1:10 in water.
 - f. When seeking medical, dental, or eye care, these persons should advise the practitioner of their positive antibody status so that appropriate evaluation can be undertaken and precautions can be taken to prevent transmission to others.
4. In colleges and universities with resident students, residence hall staff (both students and employees) should receive education about AIDS; in future years, the institution should provide that education prior to the arrival of new students.
5. Consideration of the existence of AIDS, ARC, or a positive HTLV-III antibody test should *not* be part of the initial admission decision for those applying to attend the institution.
6. The American College Health Association does not advocate the routine requirement that students be asked to respond to questions about the existence of AIDS, ARC, or a positive HTLV-III antibody test. It is, however, appropriate to encourage new students to inform campus health authorities if they have AIDS, ARC, or positive HTLV-III antibody test in order that the institution can provide them proper medical care and education. This, like all other medical information, must be handled in a strictly confidential manner in accordance with the procedures and requirements in effect in the institution.

7. College and university officials should not undertake programs of screening newly admitted or current students for antibody to HTLV-III; neither should mandatory screening of employees be implemented. Especially, institutions should not attempt to identify those in high risk groups and require screening only of them.
8. College and university health services should be familiar with sources of testing for antibody to HTLV-III, and should be able to refer students or employees requesting such testing. Health care providers should understand the capabilities and limitations of the test, and should be able to counsel those desiring to be tested or to refer them to counseling sources elsewhere. Testing should only be done where it is confidential or anonymous, where positive results can be confirmed by specific tests, and where both pre- and post-test counseling are available.
9. Decisions about residential housing of students with AIDS, ARC, or a positive HTLV-III antibody test must be made on a case-by-case basis. Those making such decisions should keep in mind the fact that AIDS is a condition present in an individual, not one that inhabits a building. **The best currently available medical information does not support the existence of a risk to those sharing dormitories with infected individuals; there may, however, be in some circumstances reasonable concern for the health of those with AIDS or ARC who might be exposed to certain contagious diseases (e.g., measles or chicken pox) in a close living situation.** Health officers in institutions with the flexibility to provide private rooms may wish to recommend that students with AIDS or ARC be assigned private rooms in the interest of protecting the health of those students. The American College Health Association recognizes that fear of AIDS may bring considerable pressure to bear on institutional housing officers, and will provide a more thorough discussion of options in the area of residential housing in a subsequent statement.
10. Guidelines concerning the handling of confidential medical information about students with AIDS, ARC, or a positive HTLV-III antibody test follow the general standards included in the American College Health Association's *Recommended Standards and Practices for a College Health Program*, Fourth Edition, 1984:

In general, it is recommended that no specific or detailed information concerning complaints or diagnosis be provided to faculty, administrators, or even parents, without the expressed written permission of the patient in each case. This position with respect to health records is supported by amendment to the Family Education Rights and Privacy Act of 1974.

Certainly no person, group, agency, insurer, employer, or institution should be provided any medical information without the prior specific written consent of the patient. Given the possibility of unintended or accidental compromise of the confidentiality of information, health officers should carefully weigh the importance of including any specific information regarding the existence of AIDS, ARC, or a positive HTLV-III antibody test in the medical record except in circumstances of medical necessity created by the evaluation of an illness. At minimum, the inclusion of any such information in the medical record should be discussed with the patient prior to its entry.

Health officials and other institutional officers must remember that all confidential medical information is protected by statutes and that any unauthorized disclosure of it may create legal liability. The duty of physicians and other health care providers to protect the confidentiality of information is superseded by the necessity to protect others only in very specific, threatening circumstances. The number of people in the institution who are aware of the existence and/or identity of students or employees who have AIDS, ARC, or a positive HTLV-III antibody test should be kept to an absolute minimum, both to protect the confidentiality and privacy of the infected persons and to avoid the generation of unnecessary fear and anxiety among other students and staff. The ACHA is now developing a statement specifically addressing the handling of confidential medical information about students with AIDS, ARC, or a positive HTLV-III antibody test in more detail.

11. There is no medical necessity for institutions to advise others living in a dormitory of the presence in the dormitory of other students who have AIDS, ARC, or a positive HTLV-III antibody test. The responsibility to provide a safe living environment is best dealt with by educational programming, as discussed earlier in this statement. Similarly, college and university officials should make no attempt in any other setting to identify those students or employees who have AIDS, ARC, or a positive HTLV-III antibody test.
12. College and university health policy should encourage regular medical follow-up for those who have AIDS, ARC, or a positive HTLV-III antibody test. Special precautions to protect the health of immunologically compromised individuals should be considered during periods of prevalence of such contagious diseases as chicken pox and measles.

13. Those who are known to be immunologically compromised should be excused from institutional requirements for certain vaccinations, notably measles and rubella vaccines, as those vaccinations may lead to serious consequences in those with poorly functioning immune systems.
14. All colleges and universities should adopt safety guidelines as proposed by the Public Health Service for the handling of blood and body fluids of persons with AIDS, ARC, or a positive HTLV-III antibody test. Those institutions which operate health care clinics and clinical laboratories providing services for students or employees should implement those Public Health Service guidelines and take measures to see that they are observed. In addition, the institution should provide educational programs about AIDS and the reduction of risk to health care providers for clinical personnel. The following articles in *Morbidity and Mortality Weekly Reports* provide detailed guidelines that should be generally followed:
 - A. Centers for Disease Control: Acquired Immunodeficiency Syndrome (AIDS): Precautions for Clinical and Laboratory Staffs. MMWR 1982; 31:577-580.
 - B. Centers for Disease Control: Acquired Immunodeficiency Syndrome (AIDS): Precautions for Health Care Workers and Allied Professionals. MMWR 1983; 32: 450-452.
 - C. Centers for Disease Control: Acquired Immunodeficiency Syndrome (AIDS): MMWR 1985; 34: 533-534.
15. College and university health services should use disposable, one-user needles and other equipment whenever such equipment will puncture the skin or mucous membranes of patients. Health care officials should not rely on students or employees to identify themselves as having AIDS, ARC, or a positive HTLV-III antibody test, since many infected persons are unaware of their status; safety precautions must be used in all cases. If disposable equipment is not available, any needles or other implements that puncture skin or mucous membranes should be steam sterilized by autoclave before reuse or safely discarded. Extreme caution should be exercised particularly in disposing of needles.
16. All colleges and universities should adopt safety guidelines for the handling of blood and body fluids of all students in other settings as well. Laboratories used in a teaching context, such as those required in biology courses, should be safe experiences. Given the fact that the existence and identity of those with AIDS, ARC, or a positive HTLV-III antibody test may not be known, procedures for the decontamination of environmental surfaces and objects soiled by blood or body fluids should be adopted and implemented. Laboratory courses requiring exposure to blood, such as finger pricks for blood typing or examination, should use disposable equipment and no lancets or other blood-letting devices should be re-used or shared. No student should be required to obtain or process the blood of others. The Public Health Service guidelines noted above include information about disinfection of environmental surfaces; a simple method they recommend is the cleaning of contaminated surfaces with a household bleach freshly diluted 1:10 in water.
17. College and university health services must strictly observe public health reporting requirements for AIDS. Patients who meet criteria for the revised surveillance definition of AIDS must be reported to the local public health authorities. The detailed surveillance definition is included in:

Centers for Disease Control: Revision of Case Definition of AIDS for National Reporting — United States: Morbidity and Mortality Weekly Reports 1985; 34: 373-375.

The Task Force on AIDS of the American College Health Association will release in the near future a series of further statements specifically addressing:

1. Residential life issues
2. Confidentiality of information and the "need to know"
3. Educational priorities
4. Administrative issues including athletic competition, institutional employees, and public relations
5. Testing, support and counseling for those at risk
6. Clinical issues for health services

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AIDS HEALTH PROJECT

TELLING OTHERS ABOUT YOUR TEST RESULTS: Some Things to Consider

If your AIDS Antibody test is positive, we urge you to seriously weigh the potential benefits and consequences of sharing these results with others. Our experience is that making a definite plan about whom to tell is important. By making such a plan you can get the most usefulness from this test result while minimizing any negative consequences. The following list of issues and considerations is meant to assist you in making the best use of this important health information.

Your anonymity has thus far been insured by your use of the Alternate Test Site. The only people who will know of your test result will be those you decide to tell.

TELLING HEALTH CARE PROVIDERS

- * If the results of your test are contained in your medical record, this information may be accessible to insurance companies when you apply for health, life or disability insurance. Considerable concern has been expressed that your insurance company's knowledge of your positive test may result in denial of future requests for coverage or benefits. (Note: While AB 403 prohibits the use of blood test results in determining insurability, in California this provision may be challenged in court.)
- * Physicians disagree as to importance of the test result for future treatment or health maintenance when the physician is already aware that the patient is a member of a high risk group.

However, for individuals with a positive result who are in a low risk group or who are experiencing symptoms associated with AIDS or ARC, the physician's knowledge of the test result may be relevant to health maintenance or future treatment.

- * You might explore your physician or health care provider's willingness to keep your test results out of your medical record before informing her/him of the result. For instance, you might ask: "If I were to take the AIDS Antibody test at an Alternative Test Site and receive a positive result, would you be willing to keep that information out of my record?" If your health care provider is unwilling to provide you with such assurance, you might want to consider seeking the services of another provider. The AIDS Hotline has listings of health care providers sensitive to this issue.

We urge you to carefully consider options which will not only protect your physical and financial well-being but also protect health care providers who are potentially vulnerable to being exposed to the virus.

- * A positive test result means you should consider yourself infectious. As such, you will want to protect your health care provider from possible exposure to the virus, as medical and dental procedures often expose health professionals to a patient's blood or other potentially infectious body fluids.

Even if you choose not to tell your health care provider about your test result, you should indicate to them that you have reason to believe you might be infectious. This will allow your provider to take precautions to protect themselves from exposure.

Should you wish to discuss this important matter with someone, call the AIDS Hotline at 863-AIDS.

AIDS HEALTH PROJECT

TELLING PARTNERS & LOVERS

As with all epidemics, the first step in elimination of the disease is control of the spread. As individuals and as a community we can take steps towards controlling the spread of the AIDS virus.

* Many researchers believe that repeated exposure to the AIDS virus may place a seropositive person at greater risk for developing full-blown AIDS. This may occur by exposing individuals to slightly different strains of the virus or by simply increasing the load of virus presented to an individual's immune system. They also expect that various co-factors such as other viral infections, use of poppers, alcohol and drugs, and generally poor health habits make individuals more susceptible to the development of AIDS.

* If partners (sexual or IV drug use) are unaware of their risk, they cannot make an informed decision about testing or health precautions. You may want to consider which individuals you would want to tell to make sure that these people are aware that they are at some risk of exposure and infection.

* You may want to talk to your sexual partners (past and present) about your sero-positive status or simply about a commitment to safe behavior. Such openness gives your partner the opportunity to make an informed decision, and to share their feelings and concerns with you.

* You may find it useful to talk about your feelings and concerns with a friend or health professional you trust. You can use this support not only to talk through your feelings and concerns, but to work with this person in a way which assists you in making and keeping your own commitments regarding safe practices.

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AIDS HEALTH PROJECT

Health Precautions for Sero-positive Persons: Safe Practices & Medical Evaluation

Limit your number of sexual partners and be aware of your partner's habits and hygiene.

Avoid sexual practices in which you and your partner exchange body fluids such as semen. The efficacy of condoms in stopping the virus is unproven but probable. There is some possibility of transmission of the virus through saliva in oral-genital contact or intimate kissing, though most researchers believe this is an unlikely method of transmission.

Intravenous drug users should limit drug usage and not share needles.

Devices that puncture the skin, such as hypodermic and acupuncture needles, should be steam sterilized by autoclave before reuse. Whenever possible, disposable needles and equipment should be used.

Avoid sharing razors, toothbrushes, or other implements that are subject to contamination with blood.

Do not donate, or make provisions for later donation of, blood, plasma, sperm, body organs, or other body tissue.

After accidents resulting in bleeding, contaminated surfaces should be cleaned with household bleach freshly diluted 1:10 in water.

Medical evaluation and follow-up is advisable. Your doctor can help you learn to recognize signs and symptoms suggestive of impaired immune functions so you and he/she can take the best possible steps to bolster your immune response and/or weaken the effect of viral infection.

Women with positive test results or who are the sexual partner of a man with positive results should avoid or postpone pregnancy since the child of a positive parent is at high risk for infection with the virus, and has an incomplete set of immune defenses to ward off AIDS or ARCs.

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AIDS HEALTH PROJECT

TELLING THE BLOOD BANK

* If you are sero-positive, you might want to contact any blood banks or plasma centers where you have given blood in the past (over 18 months ago) so that they will be sure to screen previously donated blood or blood products for the AIDS antibody.

(NOTE: This can be done discretely, e.g., inform the blood bank personnel that you believe you have been exposed and that your old donations should be screened if still 'on the shelf.' If such donations are free of antibody, no compromise of confidentiality will result using this approach.)

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* (NOTE: If you feel that there are people you would like to contact, but, for whatever reason, such a contact would be too confronting, you can get anonymous assistance from the Department of Public Health (STD Unit). They will tell your contacts: "Someone who has tested positively for the AIDS virus believes that you too may have been exposed. We want to make sure you are aware of your risk of exposure to the AIDS virus, and resources available so that you can make an informed decision about taking the antibody test yourself.")

* You may find it useful to talk about your feelings and concerns with a friend or health professional you trust. You can use this support not only to talk through your feelings and concerns, but to work with this person in a way which assists you in making and keeping your own commitments regarding safe practices.

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