Approved _____
Date

MINUTES OF THE HOUSE COMMITTEE ON FEDERAL & STATE AFFAIRS.

The meeting was called to order by Representative Robert H. Miller at
Chairperson

Noon a.m./p.m. on April 6, 1988 in room 526S of the Capitol.

All members were present except:

Representatives Sifers & Rolfs - E

Committee staff present:

Mary Torrence, Revisor's Office
Emalene Correll, Research Department
Lynda Hutfles, Secretary

Conferees appearing before the committee:

Richard Morrissey, Health & Environment
Dr. Schlousser, Health & Environment
Dr. Ray Baker, Shawnee County Health Department
Senator Dick Bond
Jerry Slaughter, Kansas Hospital Association
David Waxse, American Civil Liberties Union

The meeting was called to order by Chairman Miller.

Representative Walker made a motion, seconded by Representative Peterson, to approve the minutes of the April 4 and April 5 meetings. The motion carried.

SB678 - Effect of denial or revocation of authorization to operate a maternity hospital or home, boarding home for children or family day care homes

Richard Morrissey, Department of Health & Environment, gave testimony in support of the bill and explained that the bill would authorize the Secretary to refuse to grant a license or certificate of registration for one year following revocation or denial of an application. The bill also includes a new civil penalty authority which creates an effective sanction in lieu of revocation or denial of an application. Mr. Morrissey gave some examples of situations in which the authority to prohibit a licensee from immediately reapplying for a license would be appropriate. See attachment A.

There was discussion about changing the revocation of licenses from one year to six months. Mr. Morrissey told the committee that he had looked at what is being done in other states and the time ranges from six months to three years. His recommendation is one year. There is a need to look at quality over availability.

Representative Sprague asked if Mr. Morrissey had any problem with amending the bill to exempt out the validation procedure and Mr. Morrissey said he didn't have a problem with it, but did not think it was necessary.

When asked how these homes can stay in operation after their license has been revoked or refused, Mr. Morrissey said they could issue the final revocation order, but the homes keep on operating under other parts of the statute. The county attorney must take action after the departments final order.

Hearings were concluded on SB678.

SB686 - Requiring reporting cases of AIDS to secretary of Health & Environment and requiring testing of persons convicted of certain crimes

Dr. Schlousser, Kansas Department of Health & Environment, gave testimony in support of SB686. KDHE is the state agency responsible for investigating and controlling infectious or contagious diseases, including AIDS. The provisions

of confidentiality, the assurance of immunity from liability for reporting, the assignment of authority to the Secretary of KDHE to promulgate rules and regulations to prevent and to control AIDS and the authorization of an educational program aimed at marriage license applicants are believed to be the strengths of this bill. Dr. Schlousser suggested that AIDS tests be performed either in the state public health lab or in a lab approved by the Secretary. She also suggested that a consistant approach to the penalty provisions within the bill should be adopted. Sec. 8(b) and (c) requires AIDS testing of persons convicted of specified crimes. AIDS serologic testing can identify a true "positive" or infected person, only through a two-step process: a sensitive screening test followed by a specific confirmatory test. SB686 is a step towards coping with the AIDS threat and reflects the recommendations of the Governor's Task Force on AIDS. The Department is particularly concerned with the maternalinfant transmission of the virus. Preventive strategies to reach drug users must be developed and implemented as a means of preventing transmission of the virus to infants. See attachment B.

Dr. Schlousser also distributed a list of reportable infectious diseases in Kansas (Attachment C) and a Cumulative report of Kansas cases of AIDS reported to KDHE through February 29, 1988 (See attachment D).

There was discussion of the definition of "health care personnel". Who should or should not be told about AIDS cases. Should the dentist, hygienist, company nurse, etc., be told of AIDS cases. Will this information be forwarded to health care personnel in the event you move to another city or state. It appears there would be problems with tracking in our transient society. The question was asked whether in a hospital situation, physicians would routinely test patients for AIDS without their consent. It is not unusual in a hospital setting to order blood tests with patients consent, but without the patients knowledge of what the test is for. A patient signs a relase when entering the hospital which allows the physician to perform necessary treatment. When blood is drawn in the hospital, the norm is not to explain to the patient what the test is for. At this time, AIDS testing will not be routinely done when entering the hospital.

The committee discussed the reliability of the tests that are taken. Less than 1% of these tested have a false positive. It is still unknown how many of the people with the AIDS virus end up with AIDS. The figure used to be 10% and this has risen to 50%. The statistics are showing that persons tested for AIDS will end up with the disease.

There was concern dealing with informing every person arrested for a crime of the availability of AIDS testing. Total public education was the reason for making this so broad. There was discussion of the educational focal point. Education is directed to applicants of marriage licenses, school children and drug abusers. KDHE has 45 alternate and counseling sites across the state. They will be working with county health departments to help with this education process. There was discussion of not using the name and address of persons being reported as positive, but reporting by initial and birthdate in order to keep more confidential. Physicians reports are to be made to KDHE only after the confirmatory testing. Dr. Gary Hulett, KDHE, suggested that the committee replace "has tested positive for HIV" on line 49 with "has a positive reaction to HIV". The Chairman asked KDHE to provide a balloon of the bill with their suggested amendments.

It was suggested that the effective date of the bill be upon publication in the Kansas Register instead of in the Statute Book.

Victims rights were discussed. The victim has a right to know when and if they have been exposed to the AIDS virus.

The testing procedure was described by Dr. Carlson of KDHE. If the initial screening is positive, a second test is done with the same specimen (this is the same test done a second time). If this second test proves positive, a confirmatory test is performed. The person never knows if the results of the first test show positive unless all three tests show positive. Reporting of the initial screening should never be done. False negative results are possible and in certain cases, a second testing should be done again in a couple of months.

Dr. Ray Baker, Health Officer for Shawnee County, gave testimony in support of the bill. The development of this bill is a recognition that AIDS is a serious threat to the public health of this state. The sections dealing with confidentiality are excellent. They should help reassure and protect many who have feared their lives and reputations would be ruined by careless handling of AIDS information. The section on premarital education sets up an important educational opportunity for young people about to be married.

Dr. Baker suggested that the section requiring the Secretary to establish testing sites would be greatly improved by adding "counseling" to the activities to be undertaken. Also in order to avoid discrepency, it would be wise to delete "anonamous". Investigation, reporting and supervision of AIDS cases should continue to be through the local Health Officer. The reporting of HIV infections should be treated for purposes of disease control just like AIDS cases. See attachment E. There is no magic bullet and no miraculous cure. It is essential that KDHE have these statistices and to educate the people of Kansas.

There was discussion of quarantine. It takes seven years to develop the disease and two years to die. Supervision and education are needed.

Senator Bond told the committee that it is extremely important that the legislature address, as broadly as possible, the issue of AIDS. If they don't they will be subject to criticism. There is no cure and no vaccine. The company, Smith Cline, has developed a 100% positive test for AIDS which has not yet been approved by FDA. Senator Bond told the committee that mandatory reporting of HIV testing is over zealous and a serious mistake. He also suggested that "shall" in line 20 should be changed to "may" so that reporting to other health care personnel would be left to the discretion of the physician.

Senator Bond believes that unless their is complete confidentiality and anonimity people will not be tested. In visiting with health officials on the Missouri side who have mandatory reporting, he has been told that people are coming to Kansas to be tested so they don't have to be reported. The Buehler section in Section 8 is in another bill which is being held in Ways & Means until the outcome of SB686 has been decided. Senator Bond said it is important for the legislature to address whether or not we are going to let children in public schools in Kansas if they have the AIDS virus or disease. This question has not been addressed in the bill and it should be and he has asked Norm Furse of the Revisor's office to draft this language.

Representative Roper suggested that in Sec. 4, line 121 the definition of "health care Personnel" should be changed to "health care provider".

When asked how you can do anomous testing and then report, KDHE said you can't. This is in total conflict. All reference to HIV mandatory reporting should be stricken. The bill is in serious jeopardy if you put in mandatory HIV reporting. The local health department want mandatory reporting. The Health department needs to know who in the state is dying from AIDS. The Buehler section is unnecessary.

Jerry Slaughter, Kansas Hospital Association, expressed his support of the bill. He said it was not their intention that everyone in the hospital know that a patient has AIDS. Just the people who have the right to know. Mandatory reporting is a key part of the bill outside of the confidentiality section. Mr. Slaughter encourages open, good communication and voluntary testing. Mandatory reporting of all HIV positives will discourage people from testing. Resources need to be put where they will do the most good - Education. We can't do anything about those now infected, bu we can help the young people.

David Waxse gave testimony on behalf of the American Civil Liberties Union. He said there are two major problems with SB686. The first major problem deals with the mandatory reporting of positive HIV test results. This has no valid public health perspective and can lead to several possible deprivations of constitutional rights.

The second major problem with the bill has to do with the mandatory testing of persons convicted of certain crimes.

Only public education and a resulting change in behavior is going to provide a real solution to the AIDS problem. See attachment F. The only way to stop this disease is to follow precautions - Can't do it based on testing.

There was again discussion of school children with the disease and what should be done about them. It was suggested that a separate bill should be drafted to address that issue. There are a lot of problems arising because of the AIDS disease - housing, insurance, etc.

Written testimony was submitted by Dr. Gordon Risk, American Civil Liberties Union (Attachment G) and Jackie Sue Swearingen, owner/operator of testing facility in Garden City (Attachment H).

The hearings were concluded on SB686.

The meeting was adjourned.

A

STATE OF KANSAS

DEPARTMENT OF HEALTH AND ENVIRONMENT
Forbes Field
Topeka, Kansas 66620-0001
Phone (913) 296-1500

Mike Hayden, *Governor*

Stanley C. Grant, Ph.D., *Secretary*
Gary K. Hulett, Ph.D., *Under Secretary*

Testimony Presented To

House Committee on Federal and State Affairs

by

The Kansas Department of Health and Environment

Senate Bill No. 678

Background

When the Kansas Department of Health and Environment revokes a license or certificate of registration, it is not unusual to have the licensee/registrant immediately submit a new application for license and continue to provide child care. Health and safety violations continue, necessitating further legal action. The proposed amendments would authorize the Secretary to refuse to grant a license or certificate of registration for one year following revocation or denial of application. This authority is used in a number of other states. Benefits to improving the effectiveness of the enforcement program include: (1) greater protection of children; (2) greater stability of child care resources in the community; (3) fewer costly legal proceedings; (4) less staff time committed to problem facilities, both at the local and state level; and (5) child care is upgraded as a profession.

After a hearing and discussion of the issue, the Senate Committee on Public Health and Welfare amended the bill to include new civil penalty authority. The Department supported the amendment as a means of creating an effective sanction in lieu of having to deny or revoke licenses. It is expected that this authority would be used sparingly and would be used in situations where significant, endangering events need to be addressed. For example, a recent situation involved a toddler being left in a city park in an urban area by day care center staff. Fortunately, the child was picked up by a man who returned him to the center.

Approximately 7,000 of the 8,000 licensed child care facilities are day care and foster homes serving 12 or fewer children. For these licensees, the Department would limit any civil penalty to an amount significantly less than the $500.00 maximum. For these licensees, a civil penalty of $50.00 may well provide a substantial and actual deterrent to the noncompliant behavior. In other situations in larger facilities, a greater civil penalty might be appropriate.

Attach A

Following are several examples of situations in which the authority to prohibit a licensee from immediately reapplying for a license would be appropriate.

Registered Provider -- Statute limits the number to 6 children in care at any one time. A complaint investigation revealed eleven children under school age in care. The certificate was revoked. The provider applied for a license while continuing to provide child care. However, overenrollment continued which necessitated further legal action.

Child Care Center (60 children) - Reapplication was denied due to continuous overenrollment, violation of staff/child ratios, and health and safety violations. The center continued to operate pending submission of a new application and relicensing. Violations leading to denial continued to exist, requiring further legal action.

Group Day Care Home (12 children) - A notice of Intent to Revoke was issued based on validation of child abuse. Before an administrative hearing with SRS was held on the child abuse issue, the facility was found to be overenrolled. A second Notice was issued. The Hearing Officer found for the Department and the Secretary issued the Final Order. The provider reapplied the following week. Child care was never terminated. (Validation was withdrawn by SRS.)

Child Care Center (24 children) - A notice of Intent to Revoke was issued based on many environmental deficiencies. The Hearing Officer upheld the Department action. The center continued to provide childcare. The center owner reapplied after being ordered to by a district judge. No environmental violations had been corrected, which necessitated another Notice of Intent and Administrative Hearing.

Recommendation

We recommend passage of Senate Bill No. 678.

Presented by: Richard J. Morrissey
Director, Bureau of Adult and Child Care
April 6, 1988

STATE OF KANSAS

DEPARTMENT OF HEALTH AND ENVIRONMENT
Forbes Field
Topeka, Kansas 66620-0001
Phone (913) 296-1500

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Testimony Presented to

House Federal and State Affairs Committee

by

The Kansas Department of Health and Environment

Senate Bill 686

The Kansas Department of Health and Environment is the state agency responsible for investigating and controlling infectious or contagious diseases. AIDS is one of these diseases. We are here today to support the features of S.B. 686 that contribute to carrying out this responsibility.

Through March 1, 1988, a total of 121 Kansans have been reported to have the disease AIDS, and at least 83 of these persons are known to have died. A full accounting of the impact of AIDS must also include the number of persons who are infected with the virus but have not yet developed the disease. These infected, but seemingly well persons, are capable of spreading the disease and thus represent a significant public health risk.

Kansas is considered a low prevalence AIDS state by the Centers for Disease Control (CDC). With the concerted approach recommended by the Governor's Task Force on AIDS, it can remain so. A total of 250 persons have the HIV infection according to positive tests confirmed by the KDHE laboratory. The Kansas ratio of two infected persons to every one diagnosed case is far less than the CDC ratio estimate of fifty to one. Therefore we strongly support the expansion of testing and counseling to reach a larger segment of the high-risk population.

Broadly based educational measures are also essential. Education is currently the most potent tool available to us to break the chain of transmission of AIDS. AIDS is amenable to an educational approach because, with a few exceptions, AIDS spreads by specific, identifiable and controllable activities. This education must be of two types-- broad-based public education, and focused individualized counseling for persons who are infected or who pursue high-risk activities. S.B. 686 recognizes these needs, both directly in Section 6, which requires provision of AIDS-related educational materials to persons applying for marriage licenses, and indirectly, in Section 3, which provides the Secretary of Health and Environment with authority to adopt and enforce the necessary rules and regulations for the prevention and control of AIDS.

Attach B

We recognize the following strengths of S.B. 686:

1. The provision of confidentiality in Sections 2 (c), 3 (b), 4 (a), 5, 8 (g), and 9 (d).

2. The assurance of immunity from liability for reporting in Sections 2 (b), 4 (b), and 9 (c).

3. The assignment of authority [Section 3 (a)] to the Secretary of KDHE to promulgate rules and regulations to prevent and control this disease.

4. The authorization of an educational program aimed at marriage license applicants [Section 6].

We support the deletion of Section 10, which proclaims that AIDS is not an infectious or contagious disease, and excludes it from other state public health laws. This section was originally intended as an anti-discrimination measure to prevent the exclusion of persons with the infection from schools or child-care facilities. Currently AIDS is designated as an "infectious or contagious" disease by Kansas Administrative Regulation 28-1-2. This designation was made in 1985 in order to authorize AIDS case reporting by physicians. However, this designation creates a problem; namely, it could preclude the admittance into school or child-care facilities of infected but well children, who pose no unusual risk to their classmates. To resolve this problem, we propose amending Kansas Administrative Regulation 28-1-2 to delete AIDS as a designated infectious or contagious disease. Such a change allows the deletion of Sections 10 and 11 of S.B. 686. We are uncomfortable with the prospect of a Kansas statute stating that AIDS is not an infectious or contagious disease when we all know otherwise. Such a statement might not always be cited within the context of the entire law.

There is no problem with deleting AIDS from the regulations designating infectious or contagious diseases, provided that Sections 2 and 3 of S.B. 686 remain intact. Section 2 provides for reporting, includes measures to safeguard confidentiality of reports, provides immunity from liability for those who provide the reports, and a penalty for failure to report or for breach of confidentiality. Section 3 provides the essential authority for the Secretary to adopt and enforce rules and regulations for prevention and control of AIDS.

We have the following additional comments regarding the bill:

1. We suggest that the definitions in Section 8 (a) be placed in New Section 1 so that they apply to subsequent sections of the bill.

2. To establish and maintain a high quality control standard, we recommend that AIDS tests be performed either in the state public health laboratory or in a laboratory approved by the secretary.

3. A consistent approach to the penalty provisions within the bill should be adopted. The penalties for failure to comply or to maintain confidentiality are established as both Class A and Class C misdemeanors.

4. Section 8 (b) and (c) requires AIDS testing of persons convicted of specified crimes. AIDS serologic testing can identify a true "positive" or infected person, only through a two-step process: a sensitive screening test followed by a specific confirmatory test. The first step -the sensitive screening test- can accurately identify persons who are not infected with HIV. However if "positive " test results are reported prior to a specific confirmatory test there is the risk of a false "positive" test result.

5. Section 9 may promote a false sense of security through the requirement that bodies of persons who died of an infectious or contagious disease be so identified. This may intensify precautions when handling these bodies. However, it may lead to relaxed precautions with bodies that are infected but are dead as a result of other causes, including accidents, heart disease, etc.

S.B. 686 is a reasoned step towards coping with the AIDS threat and reflects the recommendations of the Governor's Task Force on AIDS. It may not satisfy the concerns of everyone, but we must recognize that we are in the midst of a dynamic disease phenomenon. While our knowledge of the epidemiology of AIDS has grown immensely during the past five years, the exact steps for control have not been fully defined. Of particular concern is the maternal-infant transmission of the virus. Already two infants have been diagnosed with AIDS in Kansas. Preventive strategies to reach drug users must be developed and implemented as a means of preventing transmission of the virus to infants.

Undoubtedly we will be reviewing our legislation as we learn more about the prevention and control of AIDS. Kansas is still a "low prevalence" AIDS state and S.B. 686 will assist public health officials in preventing further spread of the disease.

Presented by:

Patricia T. Schloesser, M.D.
Director of Health
April 6, 1988

REPORTABLE INFECTIOUS DISEASES IN KANSAS

AIDS
Amebiasis
Ancylostomiasis (Hookworm disease)
Anthrax
Botulism

Brucellosis
Chancroid
Chickenpox
Chlamydia
Cholera

Diphtheria
Encephalitis, Infectious (indicate infectious agent whenever possible)
Epidemic diarrhea of the newborn
Food poisoning (indicate whether infectious or intoxication and causative agent if possible)
Genital Herpes

Giardiasis
Gonorrhea
Gonorrhea ophthalmia neonatorum
Granuloma inguinale
Hepatitis type A (Infectious)

Hepatitis type B (Serum)
Hepatitis Non-A Non-B
Histoplasmosis
Kerato-Conjunctivitis, infectious
Legionellosis (legionnaire's disease or pontiac fever)

Lymphogranuloma venereum
Lymphocytic choriomeningitis
Malaria
Meningitis, aseptic and other (indicate infectious agent whenever possible)
Meningitis, Haemophilus Influenzae

Meningitis, meningococcal, including meningococcemia
Mumps
Pediculosis (louse infestation)
Pertussis (whooping cough)
Plague

Poliomyelitis
Psittacosis
Q fever
Rabies
Rheumatic fever

Rickettsialpox
Rocky Mountain spotted fever
Rubella, including rubella syndrome
Rubeola (measles)
Salmonellosis

Scabies
Shigellosis
Smallpox
Staphylococcal disease, hospital acquired
Streptococcal disease, hemolytic

Syphilis
Taeniasis and cysticercosis (beef or pork tapeworm)
Tetanus
Tinea capitis and corporis (ringworm)
Trachoma

Trichinosis
Tuberculosis
Typhoid fever
Typhus fever
Yellow fever

Any other disease which is unusual in incidence, or any disease which appears to be of public health concern, should be reported. For disease reporting, supplies and information, contact:

Bureau of Epidemiology
Kansas Department of Health & Environment
Suite 605, Mills Bldg., 109 West 9th
Topeka, Kansas 66612-1271
913/296-5586

Attach C

LEGAL AUTHORITY FOR DISEASE REPORTING
STATE OF KANSAS

COMMUNICABLE DISEASE MODEL

KSA 65-128: Authorizes Secretary to designate diseases that are "infectious or contagious" and to write rules for control.

↓

KAR 28-1-2: Designates "infectious or contagious" diseases. (See list on reverse side)

↓

KSA 65-118: Requires all persons licensed by Board of Healing Arts, and school administrators, to report diseases that are designated as "infectious or contagious." Reports are made to the local (county) health officer and must include name and address of patient.

↓

KSA 65-119: Requires the local (county) health officer to exercise supervision over all cases of infectious or contagious diseases, and to "communicate without delay all information" to the Secretary of the Kansas Department of Health and Environment.

↑

KAR 28-1-18: Requires all clinical laboratories to report positive tests for diphtheria, gonorrhea, syphilis, chlamydia, tuberculosis, typhoid fever, polio, meningococcal meningitis, and haemophilus influenzae meningitis.

CHRONIC DISEASE MODEL

KSA 65-101: Charges Secretary with "General supervision of health" and provides rule-making authority.

↓

KSA 65-102: Requires Secretary to record "forms of disease prevalent in the state."

↓

KAR 28-1-4: Requires hospital administrators to report cases of:

↓

Cancer
Congenital malformation in infants less than one year of age
Reyes Syndrome
Toxic Shock Syndrome (TSS)
Guillian-Barre Syndrome
Acquired Immune Deficiency Syndrome (AIDS)
Fetal Alcohol Syndrome

CONFIDENTIALITY OF DISEASE REPORTS

All reports made in compliance with these statutes and regulations are maintained in strict confidence, in accordance with both statutory and ethical standards. See full text of KSA 65-118 for confidentiality requirements, and for statement of immunity from civil or criminal liability for persons who provide reports.

Bureau of Epidemiology
Kansas Department of Health & Environment

01/88 RF

D

KANSAS DEPARTMENT OF HEALTH AND ENVIRONMENT
BUREAU OF EPIDEMIOLOGY
AIDS PROGRAM

MONTHLY SURVEILLANCE REPORT
CUMULATIVE KANSAS CASES REPORTED TO KDHE
THROUGH FEB 29,1988

TRANSMISSION CATEGORIES	ADULTS MALE	ADULTS FEMALE	CHILDREN	TOTAL	(%)
Homosexual/Bisexual Male	83	-	-	83	69%
Intravenous Drug User	4	1	-	5	4%
Homosexual/IV Drug User	7	-	-	7	6%
Hemophilia/Coag. Disorder	5	0	0	5	4%
Heterosexual Cases	2	2	-	4	3%
Transfusion/Blood Components	7	4	0	11	9%
Parent with AIDS/or at risk	-	-	2	2	2%
Undetermined	4	0	0	4	3%
TOTAL	112	7	2	121	100%

II. AGE AT DIAGNOSIS

GROUP	NUMBER	(%)
Under 13	2	2%
13-19	0	0%
20-29	35	29%
30-39	51	42%
40-49	21	17%
Over 49	12	10%
TOTAL	121	100%
Mean Age:		35.4

III. RACIAL/ETHNIC GROUP

	ADULTS	CHILDREN	(%)
White, not Hispanic	103	2	87%
Black, not Hispanic	12	0	10%
Hispanic	4	0	3%
Other/Unknown	0	0	0%
TOTAL	119	2	100%

IV. REPORTED CASES AND DEATHS BY OPPORTUNISTIC DISEASE GROUP

PRIMARY DISEASE REPORTED	REPORTED CASES Number	(%)	KNOWN DEATHS Number	(%)
Pneumocystis carinii Pneumonia	69	57%	44	64%
Other Opportunistic Diseases	48	40%	37	77%
Kaposi's Sarcoma	4	3%	2	50%
TOTAL	121	100%	83	69%

V. CASES OF AIDS AND CASE FATALITY RATES BY YEAR OF REPORT

	NUMBER OF CASES	NUMBER OF KNOWN DEATHS	CASE-FATALITY RATE
1982	1	1	100%
1983	2	1	50%
1984	2	2	100%
1985	16	14	88%
1986	38	28	74%
1987	55	34	62%
1988	7	3	43%
TOTAL	121	83	69%

VI. CASES OF AIDS AND CASE FATALITY RATES BY COUNTY OF RESIDENCE (Counties with 10 cases (or more)

	NUMBER OF CASES	NUMBER OF KNOWN DEATHS	CASE-FATALITY RATE
Johnson	29	16	55%
Wyandotte	27	18	67%
Shawnee	13	11	85%
Sedgwick	22	17	77%
All Others	30	21	70%
TOTAL	121	83	69%

VII. AIDS CASES PENDING AT CDC: 14

Attach D

ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS)
WEEKLY SURVEILLANCE REPORT
UNITED STATES CASES REPORTED TO CDC

As of February 29, 1988

I. TRANSMISSION CATEGORIES

	ADULT MALES	ADULT FEMALES	TOTAL	(%)	CHILDREN	(%)	TOTAL
Homosexual/Bisexual Male	34,687	-0-	34,687	64%			34,687
Intravenous Drug User	7,406	2,067	9,473	18%			9,473
Homosexual/IV Drug User	4,016		4,016	7%			4,016
Hemophilia/Coagulation Disorder	530	22	552	1%	48	1%	600
Heterosexual Cases	987	1,182	2,169	4%			2,169
Transfusion/Blood Components	845	452	1,297	2%	118	14%	1,415
Parent with AIDS/or at risk					663	77%	663
Undetermined	1,311	353	1,664	3%	36	4%	1,700
TOTALS	49,782	4,076	53,858	100%	865	100%	54,723

II. AGE AT DIAGNOSIS BY RACIAL/ETHNIC GROUP

AGE GROUP	WHITE, NOT HISPANIC	(%)	BLACK, NOT HISPANIC	(%)	HISPANIC	(%)	OTHER UNKNOWN	(%)	TOTAL	(%)
Under 5	135	0%	419	3%	174	2%	7	1%	735	1%
5 - 12	59	0%	48	0%	21	0%	2	.0%	130	0%
13 - 19	106	0%	82	1%	40	1%	5	1%	233	0%
20 - 29	6,240	19%	3,299	24%	1,720	23%	88	17%	11,347	21%
30 - 39	14,915	46%	6,682	48%	3,539	47%	222	44%	25,358	46%
40 - 49	7,378	23%	2,401	17%	1,455	19%	125	25%	11,359	21%
Over 49	3,915	12%	1,011	7%	578	8%	57	11%	5,561	10%
TOTALS	32,748	60%	13,942	25%	7,527	14%	506	1%	54,723	100%

III. REPORTED CASES AND DEATHS BY OPPORTUNISTIC DISEASE CATEGORY

DISEASE CATEGORY REPORTED	CUMULATIVE CASES/DEATHS Reported Cases Number	(% Total)	Known Deaths Number	(% Deaths)
Pneumocystis Carinii Pneumonia	34,130	62%	19,381	57%
Other Opportunistic Diseases	14,743	27%	8,570	58%
Kaposi's Sarcoma	5,850	11%	2,764	47%
TOTALS	54,723	100%	30,715	56%

IV. CASES OF AIDS AND CASE-FATALITY RATES BY YEAR OF DIAGNOSIS

	NUMBER OF CASES	NUMBER OF KNOWN DEATHS	CASE-FATALITY RATE
1981	271	249	92%
1982	1,023	898	88%
1983	2,833	2,510	89%
1984	5,720	4,680	82%
1985	10,236	7,732	76%
1986	15,558	8,835	57%
1987	18,510	5,694	31%
1988	497	53	10%
TOTALS	54,723	30,715	56%

E

Presentation to House Federal and State Affairs Committee on Senate Bill #686, April, 1988.

I'm Dr. Ray Baker, Health Officer for Shawnee County; I appreciate this opportunity to testify on SB #686.

The development of this bill is a recognition that AIDS is a serious threat to the public health of this state and nation. Obviously, the legislature wants to respond positively to the well-founded concerns of Kansas citizens.

This is a very good bill: I'd like to comment on several areas that are particularly commendable.

The Sections dealing with confidentiality are excellent. They should help reassure and protect many who have feared their lives and reputations would be ruined by careless handling of AIDS information. That reassurance, in turn, ought to improve trust and cooperation between patients, public health officials and practicing physicians, which is vital to any program of control.

The section on Premarital education is an excellent compromise. It avoids costly and -- at this point -- probably minimally productive premarital screening, and instead sets up an important educational opportunity for young people about to be married.

Third, this Section requiring the Secretary to establish testing sites is highly desirable. It would be greatly improved by adding "counseling" to the activities to be undertaken; also in order to avoid the discrepency, with mandatory reporting it would be wise to delete "anonamous".

Section 2(a) and 3 (a) which require reporting, investigation and supervision of AIDS cases should continue to be through the local Health Officer. Any of AIDS cases should continue to be through the local Health Officer. Any local health officer who feels unable to cope with these obligations in his/her county can -- and should -- call on the Secretary for assistance. But, by the large control and investigation of disease outbreaks are far better done locally.

Finally there is one public health tool that has been inserted into this bill that is critical: The reporting of HIV infections. They should be treated for purposes of disease control just like AIDS cases. Let me tell you why. CDC has made careful estimates that there are 50 to 100 HIV positive individuals (carriers) for every AIDS case in this country....That means there are 6000 to 12,000 carriers in Kansas. Each is capable of spreading the AIDS virus probably far more efficiently and extensively than AIDS patients who are often quite weak, ill and homebound. Since there is very unlikely to be an effective vaccine of drug against AIDS for many years, it is absolutely essential that public health officials be given the tools to measure the extent and location of the problem, identify the carriers and cases and concentrate our educational and control efforts where they will do the most good.

Attach E

It may already be too late for areas like New York and San Francisco to use (because their numbers are mind boggling) but CDC believes it is precisely in low incidence area like Kansas where case and carrier reporting and contact tracing and counseling will well work to slow this disease.

I realize there is great fear that reporting of carriers will discourage testing and that is an outcome none of us want; but the State Department of Health and Environment has just gathered recent statistics from 3 states that have inaugurated manadatory reporting of HIV. Contrary to the expectations of civil libertarians all states reported substantial increase in testing afterward.

Of course, we need to continue mass education, but that's not enough; we need to take the next step and supplement it by more precise and intense activities.

Ladies and Gentlemen of the committee, I applaud your efforts to stop this frightening disease and hope my comments will assist you in your deliberations.

F

TESTIMONY OF DAVID J. WAXSE ON BEHALF OF
THE AMERICAN CIVIL LIBERTIES UNION
BEFORE THE FEDERAL AND STATE AFFAIRS COMMITTEE OF
THE KANSAS HOUSE OF REPRESENTATIVES
RE: SENATE BILL #686
WEDNESDAY, APRIL 6, 1988

My name is David J. Waxse and I am here today on behalf of the American Civil Liberties Union. I am a member of the national ACLU AIDS Task Force and serve as General Counsel of one of the local ACLU affiliates. Since all of that work is done on a volunteer basis, I also continue to practice law in Johnson County, concentrating primarily in employment law and civil rights law.

From our perspective there are two major problems with Senate Bill No. 686 as it presently is written. The first major problem has to do with the mandatory reporting of positive HIV test results. This requirement has no valid public health purpose and in fact will be counter productive from a public health perspective. Additionally, it can easily lead to several possible deprivations of constitutional rights.

To understand why this provision has no valid public health purpose requires an understanding of the problems with HIV testing generally.

In order to understand what information HIV testing provides, one must first understand AIDS itself. AIDS is caused by a virus known as the HTLV-III virus and commonly referred to

Attach F

as HIV or Human Immunodeficiency Virus. Not all persons infected with the virus will develop AIDS or AIDS related complex (a milder form of the disease). All persons infected become what is known as "seropositive." A person is seropositive if blood tests reveal the presence of antibodies to HIV. Most people infected with the virus will become seropositive within six weeks to three months of infection, although some will take as long as one year. It is estimated that, at this time, at least 1.5 million persons in the U.S. are seropositive. Although seropositive persons may not suffer any symptoms, they do carry the virus and may be capable of transmitting it to others. Presently there is no "treatment" available for persons who are simply seropositive.

A seropositive person may eventually develop AIDS or ARC. The incubation period (the time between the initial infection and the onset of symptoms) ranges from about six months to five years. Because AIDS is such a new disease, the medical profession cannot predict with any certainty how many people who test seropositive will eventually suffer from AIDS itself. The evidence at this time indicates that the vast majority of infected people remain healthy five years after infection. It is projected that only 25 to 50% of seropositive persons will develop AIDS, and this will occur within five to ten years of infection.

Blood testing today consists of testing for the presence of HIV antibodies. The test does not identify persons with AIDS or ARC, nor does it predict whether the person will ever develop AIDS or ARC in the future. Furthermore, the test fails to identify an individual as seropositive during the time period between infection and the development of antibodies. The test also fails to identify as seropositive those persons whose immune systems are so damaged by the virus that they are no longer producing antibodies.

To understand what is actually involved in a test for antibodies, it may help to think of another situation. All persons who have received polio vaccines will test positive for polio virus antibodies. Obviously, these people have developed a resistance to polio and are not a risk but the point is that a test for an antibody is not a test for a disease.

In addition to these failures, the test can also result in false positives for many reasons. Certain medical conditions, such as malaria and hepatitis, may cause a positive result. Furthermore, there is always the possibility of a false positive caused by contamination or technician error. Outside of the higher risk categories of male homosexuals and IV drug abusers, the false positive rate has been very high in some studies. (See the attached Articles from the July 23, 1987 Washington Post.) There is also the problem of false negatives to consider.

In addition to the problems innate to the testing process there are several other problems that make mandatory reporting a counter productive public health measure which will undermine our efforts to contain the spread of AIDS.

The first problem is that mandatory reporting--especially in the absence of nondiscrimination guarantees--will scare people away from testing and counseling sites and thereby undermine the success of voluntary testing programs. The goal of voluntary testing programs is to reach individuals at risk for AIDS. Most such individuals are already in minority groups fearful of the government and fearful of the additional discrimination they would face if they were discovered to have AIDS. If name reporting were instituted, these persons, before seeking a test, would need to consider whether they wanted their names reported to the government. Preliminary studies show that the loss of confidentiality brought about by name reporting is the greatest single barrier to individuals seeking HIV antibody tests and counseling. For instance, in a study of gay men in Colorado who chose not to seek antibody testing, 36.1% of these men cited the Colorado reporting statute as their reason for not being tested; no other reason was cited by more than 11% of the respondents. Schultz, "Reasons for Choosing Not to be Tested for the HTLV-III Antibody: A Study of Gay and Bisexual Men" (unpublished thesis abstract, 1987) (attached). See also

Martin, "Causes and Consequences of Testing for HTLV-III Antibody: The Gay Community Experience," in Impact of Routine HTLV-III Antibody Testing on Public Health (NIH Consensus Development Conference Program and Abstracts, July 7-9, 1986) at 73-76 (attached).

The second problem is that in practice, mandatory reporting has led to a drop-off in testing. For instance, Illinois showed a sharp drop in the number of persons seeking voluntary HIV tests after the legislature there passed a name reporting statute. See "Rumors raise havoc with AIDS testing programs," Chicago Tribune, August 5, 1987 at 2 (attached). In Colorado, which is often touted as a success story because name reporting reportedly has not greatly diminished the number of persons coming into test sites, the state's policy is to advise people they can give false names, which many do. The Colorado system would not work without this allowance of false names. It could more accurately be called pseudonym reporting.

The third problem is that people fear that their confidentiality won't be protected because lists can be stolen and because, once the list exists, there can be no assurance that legislatures won't pass future laws permitting persons other than public health officials from having access to it. Once the government has a list of the names, addresses, sexual preferences and other information about people who test positive for the AIDS

virus, that list would become an irresistible target. In fact, some lists have been stolen. See "Thieves Steal Computer Containing Confidential List of 60 AIDS Victims," Los Angeles Times, July 9, 1987 at 3 (attached); "Log, Said to List AIDS Test-Takers, Is Lost," New York Times, April 23, 1987 at A21 (attached). In addition to the problems of theft and unauthorized disclosures, there is no way to guarantee that, whatever the confidentiality protections today, future laws won't be passed to allow insurers, school systems, or other state agencies to have access to such a list. Once a list is created its very existence leads to calls for access to it. This in turn will lead to discrimination, even against people who, though infected, don't have AIDS and may never get it.

The fourth problem is that name reporting does not advance the goal of gathering more complete epidemiological (disease pattern) data on the incidence of HIV infection in this state. First, by scaring people away from being tested, it is likely to result in less, not more, information. Second, although health officials do need more information about the incidence of infection, what they need is numbers, not names. A better way to get that information is through a combination of anonymous test sites reporting data and a sentinel hospital study like the ones being done by CDC and New York state. Third, name-associated data is likely to be skewed and thus less

reliable for that reason. Name-associated data only tells us how the number of infected patients of those doctors who are actively participating in reporting. Even with less controversial STDs, there is considerably skewed reporting--middle class patients convince their physicians not to comply while those attending public health clinics have little choice.

The fifth problem is that, in truth, name reporting is often advocated for precisely the reason people fear--as a precursor to more repressive measure. Senator Helms admitted on CBS's Face the Nation that the reason to collect names is ultimately so the government can isolate those who are positive. This type of traditional public health strategy--mandatory testing, name reporting, contact tracing, notification, and isolation--might make sense for other diseases; it does not for AIDS because it would be prohibitively expensive and do little to control the spread of the disease. Without epidemiological value and without a traditional public health purpose, there is no rationale for name reporting.

Finally, some people have argued that mandatory reporting is required in order to institute mandatory contact tracting programs.

Contact tracing is a counterproductive public health measure for the following reasons:

(1) Contact tracing would drive people away from voluntary testing sites. Knowing that the state will be seeking the names of all one's past and present sexual partners will discourage people from being tested. Moreover, voluntary testing campaigns depend on assuring the confidentiality of the person tested. Trust in the protection of confidentiality is likely to diminish when the testing site is thought of as a place where names are collected.

(2) Contact tracing depends on the cooperation of the tested person. There is little a health official can do to force a person to identify truthfully and accurately all of his/her sexual contacts. Thus "requiring" contact tracing, that is, a policy of "requiring" the collection of names from each person tested is no more likely to achieve its ultimate goal of notification than a voluntary model, and is probably less likely to do so. A voluntary counseling approach is more likely to elicit honest discussion of who needs to be notified and how best that can be accomplished. Overall, the model that is most coercive is most likely to backfire both in the short run and the long run. Individuals leaving a coercive process will be even less likely or able to deal with the responsibilities of partner notification in future situations.

(3) Contact tracing for AIDS is different than tracing for syphilis or gonorrhea because AIDS has such a long incubation period--at least five years and possibly more. Thus, contact tracing for partners of HIV infected individuals would involve attempting to identify and then to locate sexual partners for the past decade or so. This makes tracing for AIDS contacts much more cumbersome, costly, and inefficient.

(4) AIDS is also distinguishable from syphilis and gonorrhea in that the primary purpose for contact tracing--to identify and provide treatment to infected individuals--is inapplicable to HIV infection. There is as yet no way to cure HIV or to render it non-communicable. Those infected can only be provided with information. While that is an important goal, person-to-person contact tracing, with only those who voluntarily seek testing as a base, will never reach most persons at risk. It is no substitute for massive public education efforts.

Finally, mandatory reporting, with or without the possibility of contact tracing, raises grave constitutional and civil liberties concerns because it involves the state in list keeping which could exacerbate discrimination. Once the state has a list of the names, addresses and whatever other information is obtained through contact tracting of people who test positive

for the HIV virus, that list would become an irresistible target for some governmental officials. There is no way to guarantee that, whatever the confidentiality protections today, future laws won't be passed to allow access to such a list. Once a list is created its very existence leads to calls for access to it. The best protection is to not create such a list in the first place.

A second major problem with the bill has to do with the mandatory testing of persons convicted of certain crimes.

Because the law is silent as to its intended purpose, one can only guess as to how this limited information will be used. Conceivably, it could be used to identify those offenders who are seropositive and who need medical attention or counseling to reduce the spread of the disease. Certainly, these are laudable goals. If these were the real goals of the law, however, there would be no reason for the test to be involuntary; the offenders would be given the <u>opportunity</u> to be tested rather than <u>forced to submit</u> to the test. One can only assume then that the purpose of the testing is to benefit the victim rather than the offender.

Most likely, the purpose of the proposed law is to provide the victim with information about the offender's antibody status, and thus, the victim's status. However, because of the high danger of both false positives and negatives, such testing will give the victim little peace of mind. Quite conceivably,

the offender may have infected the victim and yet the offender may still test negative because he or she has not yet developed the antibodies. The victim is likely to rely on this false information and may unwittingly transmit the virus to others. On the other hand, a false positive may cause unnecessary severe emotional distress to the victim and actually increase the damage.

On the other hand, when the offender correctly tests positive, the victim is provided with little information. First, such a positive result does not indicate whether the victim is infected with the virus--it only indicates that the offender was infected at the time of testing. It is possible that the offender became infected with the virus after the criminal sexual contact with the victim and, thus, never infected the victim. Second, even if there is reliable evidence that the offender was infected at the time of the sexual contact with the victim, a positive result in no way indicates that the victim will actually be infected by the virus or contract the disease itself. Statistically speaking, the chances of the victim contracting the disease itself are small. Finally, even if the virus has actually been transmitted to the victim there remains the problem that with present medical knowledge there is no specific treatment that can be taken to keep the disease from developing. Thus the question remains what has been accomplished.

In conclusion, these proposals have no valid public health purposes and may instead create numerous problems relating to constitutional rights and civil liberties. In addition, these proposals mislead the citizens of the state into thinking something is being done about AIDS when nothing worthwhile is being accomplished. Only public education and a resulting change in behavior is going to provide a real solution to this problem.

AIDS 'False Positives': A Volatile Social Issue

Low-Risk Groups May Have High Error Rate

By Susan Okie
Washington Post Staff Writer

Inside the Military Entrance Processing Station in Linthicum Heights, Md., one day last week, a throng of shirtless young men waited to have their blood drawn. When a white-suited technician called out, "Next physical," another recruit would slide onto a stool and extend his arm. Deftly, the gloved technician tightened a tourniquet around the recruit's biceps and slipped a needle into a vein. Blood spurted into a vaccum-sealed tube.

The tube was spun in a centrifuge to separate the cells from the yellow fluid called serum, which was then poured into a numbered vial and shipped, along with dozens of other samples, to the laboratory that tests the blood of military applicants for exposure to the AIDS virus.

That procedure is repeated many times a day at the Maryland center and others like it around the country. Since it began almost two years ago, the Defense Department program has tested about 2½ million people and has become the prototype for proposals to test engaged couples, hospital patients, immigrants and other groups. Its scientific standards are rigorous, the quality of the laboratory work is scrupulously monitored, and the results are impressive. Even so, no medical test is perfect.

Out of every 100,000 military applicants, about 150 test positive for infection with the AIDS virus. Between one and three of those 150 are "false positives," meaning that the tests indicate incorrectly that they have the AIDS virus. That estimate is based on using a variety of other laboratory tests to verify positive results and on following up samples that are equivocal with repeated tests.

"Everybody wants it to be a perfect test," said Dr. Donald Burke, chief of virus diseases at the Walter Reed Army Institute of Research. "That just ain't life."

The problem of false positives has received scant attention from advocates of widespread AIDS testing, but many public health experts predict it will have explosive implications if testing is expanded to include groups at very low risk of the infection.

"No one has asked the question, 'How many errors can we tolerate?' " said Dr. Stephen G. Pauker, a professor of medicine at Tufts University Medical School.

In an article published today in the New England Journal of Medicine, Pauker and Dr. Klemens B. Meyer, a colleague at New England Medical Center, predict that false positive rates will rise if lower-quality laboratories are used, if increased demand overburdens laboratories and if a new test is introduced as a substitute for the present, two-stage testing procedure.

Pauker said the false positive rate is critical in programs to test groups at very low risk of infection with the virus, such as marriage applicants in areas of the country with few AIDS cases or elderly patients scheduled to have elective surgery. In such groups, he said, the false positives could easily outnumber the true positives.

"The false positive rate will go up to some extent" as testing becomes more widespread, he said. "It doesn't need to go up very much to create a social catastrophe."

Current AIDS testing programs involve two tests, done sequentially. The first, the ELISA, is a simple screening test sensitive enough to detect almost all infected individuals, but it yields a high rate of false positives. If the ELISA is positive, it is usually repeated to verify the result. If the repeat is positive, then a different test, the Western blot, is used. This test has a much lower rate of false positives than the ELISA, but it is more complicated and expensive. Repeating the Western blot, trying to culture the virus and performing other blood tests can provide additional information but cannot prove with certainty that an individual result was a false positive.

"To prove absolutely that somebody is truly not infected, when all tests are positive—there's just no way to do it," said Dr. Harvey Fineberg, dean of the Harvard School of Public Health.

The estimated false positive rate of one to three out of 100,000 is based on individuals who have gone through the whole testing sequence.

False positive tests make up a much larger proportion of all positive tests among people at low risk of contracting AIDS, such as couples about to be married, than in high-risk groups such as homosexual men or drug addicts, according to public health experts. For that reason, the decision to test such low-risk groups involves a tradeoff. To identify people infected with the AIDS virus, some uninfected individuals will be falsely labeled as carriers and will suffer the emotional and social consequences.

Because recipients of the false results would believe themselves infected, Pauker said, they might choose not to marry or have children. Their careers and insurance coverage could also be affected. In their article, Pauker and Meyer ask, "How many engagements should end to prevent one infection? How many jobs should be lost? How many insurance policies should be canceled or denied? How many fetuses should be aborted and how many couples should remain childless to avert the birth of one child with AIDS?"

Burke argues that the track record of the military program shows that widespread testing can nevertheless be successful if done very carefully.

"Critics of testing have said [it's] logistically unfeasible, economically unsound and inaccurate. All of those are untrue," he said.

But he added, "I'm not sure that we are nationally ready to implement screening programs. It's not because we can't. It's because we haven't devoted the attention to make damn sure that the tests work very well" at all the laboratories involved.

Both the ELISA and the Western blot measure antibodies against the AIDS virus present in the blood. Such antibodies usually develop between three and 12 weeks after an individual becomes infected with the virus.

Burke said the quality of the tests, particularly the Western blot, varies greatly among laboratories. The Western blot's false positive rate depends both on how well it is done and on the strictness of criteria for calling a test positive. The test can show a pattern of one or more bands or stripes corresponding to antibodies against different proteins in the human immunodeficiency virus (HIV), the cause of AIDS.

Some laboratories consider a test positive if just one band is visible, which increases the likelihood of false positives. Burke said the military program is about to change its criteria to require the presence of two bands. The American Red Cross requires three bands, according to Dr. James Auhuchon, a medical officer there.

Based on research in the military program, Burke estimates that the proportion of positives that are false is about 2 percent, according to Burke.

Thus, if a military applicant tests positive, "there is a 97 to 98 percent chance that they really are infected," he said.

But some public health experts, including Pauker and Fineberg, contend that even a false positive rate of three in 100,000 could be a major problem if the population being tested had a very low incidence of infection with the AIDS virus.

For example, American Red Cross statistics show that 10 of every 100,000 potential blood donors test positive for the AIDS virus. Donors who test positive are notified, and their blood is rejected. If the false positive rate were three out of 100,000, it would mean that three of those 10 positive tests, or 30 percent, were in error.

AuBuchon said the American Red Cross program considers all its positive Western blots to be true positives. "There aren't false positives," he said. He said he was unaware of any studies to the contrary.

Dr. Harold Jaffe, chief of AIDS epidemiology at the Centers for Disease Control, said the success of the military screening program had persuaded CDC officials that the false positive rate can be kept acceptably low. "I think our general feeling is, it's not really that much of an issue," he said.

At the military processing center in Linthicum Heights, Capt. Michele Welles, the Army medical administrative officer, said that if a blood sample tests positive on two ELISA tests and a Western blot, the applicant is notified and the Western blot repeated on a second sample. She said that if that is also positive, the applicant is disqualified from military service. She said a doctor at the station talks with such applicants individually, advising them to see a civilian doctor for further evaluation.

Burke said he is pleased with the results of the military program but acknowledged that similarly high standards might not be achieved by other testing programs. He said that the problem of false positives in AIDS testing is no different from those encountered with other diagnostic tests.

"What it means is, if we are going to go ahead we're going to have to make sure that we do it right," he said.

TESTING FOR INFECTION WITH THE AIDS VIRUS

The AIDS virus contains proteins. If a person becomes infected with the virus, his immune system starts manufacturing antibodies to tag these proteins. The process takes three to 12 weeks.

The two test procedures described below involve measuring the presence of antibodies in the blood.

THE ELISA TEST

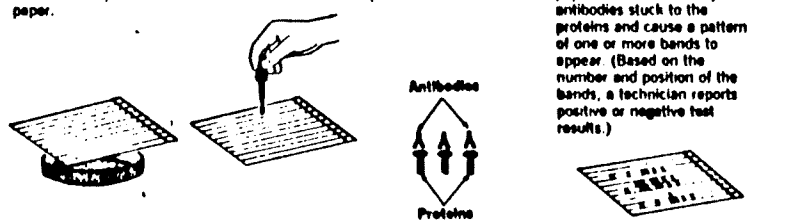
(Enzyme-Linked Immunosorbent Assay; the most common screening test for infection)

1. Proteins from the AIDS virus are spread onto tiny plates or beads.
2. A sample of the blood to be tested is poured into small wells containing the protein-coated plates/beads.
3. If antibodies are present in the blood, they stick to the proteins.
4. A detecting antibody is then added to the wells. It will bind to any antibodies stuck to the proteins and cause a change of color. (Based on the color, the laboratory reports positive or negative test results.)

THE WESTERN BLOT

(Used to confirm a positive ELISA test)

1. Proteins from the AIDS virus are separated in a gel and blotted onto special paper.
2. A sample of the blood to be tested is applied to the paper.
3. If antibodies are present in the blood, they stick to the proteins.
4. A detecting antibody (radioactive or chemically treated) is then added to the paper. It will bind to any antibodies stuck to the proteins and cause a pattern of one or more bands to appear. (Based on the number and position of the bands, a technician reports positive or negative test results.)



BY JO ELLEN GRIFFIN—THE WASHINGTON POST

Schultz, Judith M. (M.S., Nursing)

Reasons for Choosing Not to be Tested for the HTLV-III Antibody: A Study of Gay and Bisexual Men

Thesis directed by Assistant Professor Joan K. Magilvy

In this descriptive, cross-sectional study, a convenience, snowball sample of 97 gay and bisexual men in Denver was recruited to identify reasons given for choosing not to be tested for HTLV-III antibodies, the laboratory test currently used to determine exposure to the virus responsible for the Acquired Immunodeficiency Syndrome (AIDS).

The sample was mostly Caucasian (86.6%), 26-45 years old (80.4%), and homosexual (91.8%). Marital status included: single (58.8%), homosexual coupled (38.1%), and heterosexual married (3.1%). One respondent reported symptoms thought due to AIDS Related Complex (ARC); none reported symptoms related to AIDS. Many respondents knew someone who had died of AIDS.

The self-administered questionnaire asked about sexual activity and beliefs about the antibody test, as well as reasons for choosing not to be tested. Reasons for not being tested cited as most important were: Colorado reporting law (36.1%); fear that results would cause worry (11.3%); that test results make no difference

in preventive measures (7.2%). Others cited most frequently were: possible loss of insurance coverage (74.2%); that test indicates only antibodies, not virus (72.2%); possible inaccuracy of test (66.0%). No association between reasons and age, ethnicity, sexual behavior, or beliefs was found.

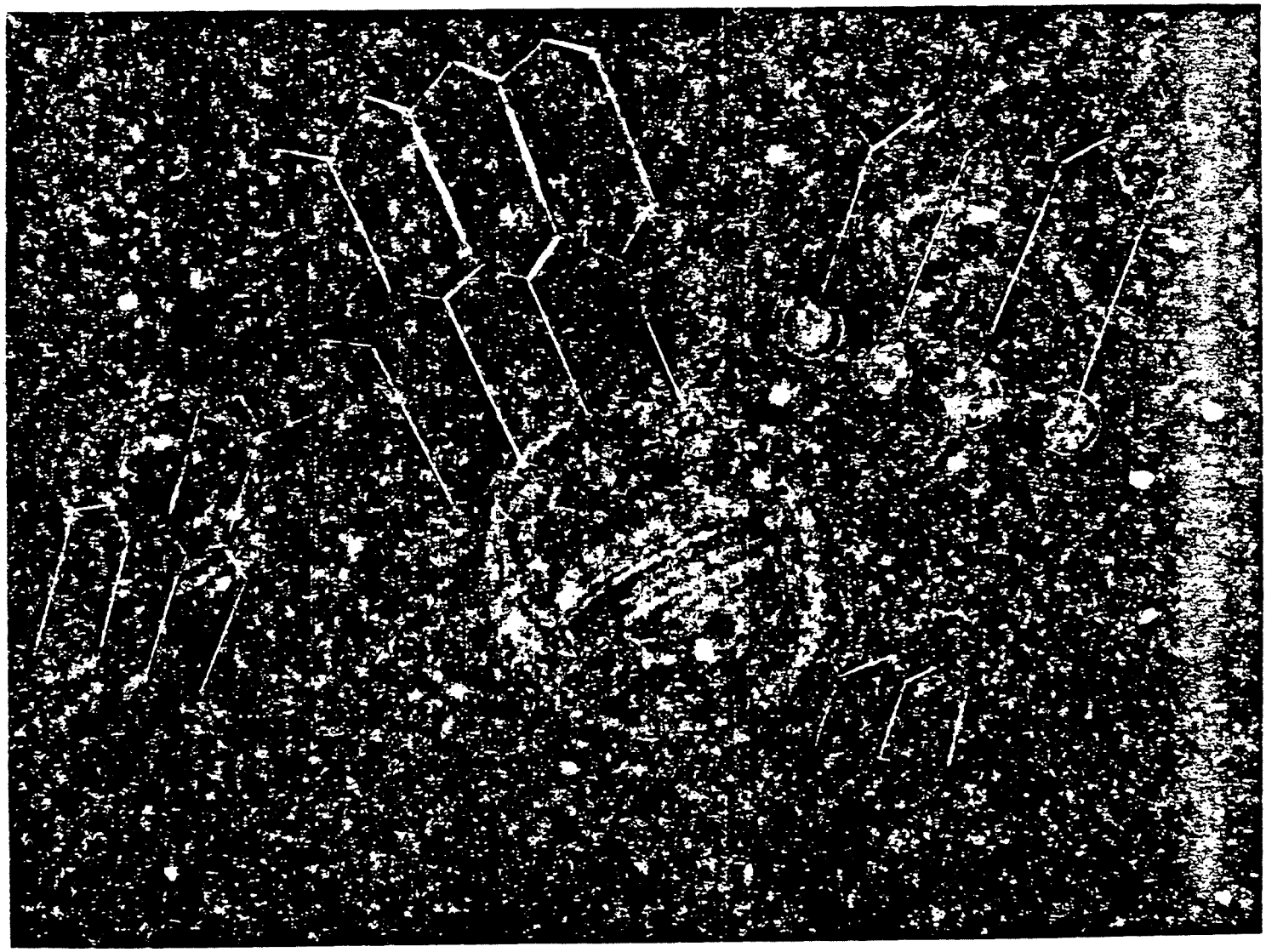
Discussion included the Colorado reporting law, education, and funding for HTLV-III related medical care. The study has significance for community health nurses, public health professionals, and policy makers.

The form and content of this abstract are approved.

Signed _____
Faculty member in charge of thesis

NIH Consensus Development Conference

Impact of Routine HTLV-III Antibody Testing on Public Health



Program and Abstracts

July 7-9, 1986

Causes and Consequences of Testing for HTLV-III Antibody: The Gay Community Experience

John L. Martin

A sample of 745 gay men who did not have AIDS were enrolled in a prospective study of the social, psychological, and behavioral impact of the AIDS epidemic on the New York City gay community. Initial interviews were conducted in mid-1985. A longitudinal serologic/immunologic study was subsequently added to the psychosocial study to assess HTLV-III/LAV antibody status, various hematologic characteristics, and T cell phenotypes. Participants for this substudy were recruited from the cohort of 745 and were offered the option of finding out their antibody status. A total of 350 enrolled and initial baseline blood samples were drawn in early 1986. At the time each sample was taken participants were asked a variety of questions about their intention to seek test results, their anticipated antibody status, and their intentions regarding changes they expect to make based on their antibody status. Approximately 50 percent of those enrolled in the serologic study indicated that they intended to find out their antibody status. The remaining 50 percent either said they did not know whether they would seek this information or said they were determined to not seek their results.

At this time only a portion of the data are available for analysis. Thus, results described here must be regarded as preliminary and are subject to change when analyses are conducted on the complete data set. Three main questions can be addressed at this time: (1) What factors lead gay men to avoid antibody testing? (2) What are the characteristics of gay men who seek testing? (3) What is the impact of knowing one's antibody status on mental health and sexual behavior?

In order to determine factors associated with avoiding testing, reasons for refusing to enroll in the serologic study were analyzed for content and classified into four mutually exclusive categories. The most common reason for refusing (40 percent of all reasons) was concern over confidentiality of test results. In spite of the fact that this study employs a system which assures anonymity many respondents felt that if government agencies or insurance companies decide to compile lists of antibody-positive individuals no method of protecting confidentiality could be considered 100 percent effective. The second most common reason for refusing to participate (20 percent of all reasons) was concern over personal psychological well-being. Although respondents were given the option of participating in the serologic study for research purposes

only, without having to be informed of their antibody status, a number of men expressed concern that they would not be able to resist knowing the result if it were available. Many respondents said they simply felt overwhelmed by AIDS-related issues and could not cope with the additional stress associated with testing. The third most common reason for refusing (12 percent of all reasons) was simply distrust in the accuracy and reliability of the test. (This reason was given in spite of the fact that Western blot confirmation following two positive readings based on the ELISA assay are required in order to be classified as antibody-positive.) The remaining reasons for refusing to participate varied widely and included dislike of the study itself, general opposition to all blood testing, and fear of needles.

To address the question of what type of gay man is most likely to seek antibody testing, two groups were compared: (1) men who enrolled in the serologic study specifically to find out their antibody status, (seekers, N = 97), and (2) men who enrolled for research purposes only or men who elected not to enroll at all, (nonseekers, N = 534). These two groups were compared on sets of variables measuring background and demographic characteristics, sexual behavior activity levels, involvements with persons with AIDS, and psychological distress. No differences between the two groups were found for age, education, income, ethnicity, lover status, or veteran status. Nor were any significant differences between the two groups found on variables representing the number of sexual partners, frequencies of engaging in specific sexual activities, or frequency of condom use, either before hearing about AIDS (1980-81) or in the year prior to the interview (1984-85).

Differences were found, however, in two other areas. A significantly larger proportion of those seeking their antibody status reported having a close friend or lover sick with AIDS (20 percent) compared with the group of nonseekers (11 percent; $p < .02$). In addition, significant differences were found on measures of subjective vulnerability to AIDS and psychological distress related to the fear of AIDS. Specifically, compared to nonseekers, seekers of antibody test results report lower levels of subjective threat of developing AIDS ($p < .02$) and lower levels of psychological distress symptoms involving intrusive and avoidant thoughts about AIDS, panic attacks, thoughts of dying, and dreams and nightmares about AIDS ($p < .04$).

These results indicate that the type of gay man most likely to seek HTLV-III antibody testing is more likely to be close to someone with AIDS and to be comparatively better defended, psychologically, against the threat of AIDS. The lack of significant differences between seekers and nonseekers on sexual behavior histories and background factors suggests that entry into testing programs by gay men is not influenced by the likelihood of being antibody-positive or antibody-negative.

The question of the impact of knowing one's antibody status on mental health and sexual behavior is the question least amenable to being

addressed with the available data. Two analytic approaches were taken to generate convergent evidence. The first approach involves content analyses of anticipated changes described by serological study participants. Of those men who intend to seek their antibody status, 39 percent plan to make changes in their lives should they be antibody-positive; 11 percent intend to make changes if they are antibody-negative. The changes the men intend to make if they are positive can be classified, in descending order of frequency, as follows: (1) more careful in sexual behavior, (2) more attentive to health behaviors and more frequent use of medical services for health monitoring, (3) initiation of financial arrangements for the future, execution of a will, and preparation for death, and (4) changes in psychological and philosophical approaches to life. It is important to note that 61 percent of those who intend to seek their antibody status said they do not intend to change anything about their lives. In most cases the reason for this is that they had changed all relevant aspects of their sexual behavior so that there was nothing left to change.

The second analytic approach taken to the question of knowledge impact involves comparing the following three groups: (1) men who knew they were antibody-positive at the time of the initial interview (N = 16), (2) men who knew they were antibody-negative at the time of the interview (N = 34), and (3) men who had not been tested at the time of the interview but who subsequently enrolled in the serologic study with the intention of knowing their antibody status (N = 97). The data were collected in a way that does not allow firm conclusions to be drawn from the lack of differences between these groups. The reason for this is that respondents who knew their antibody status at the time of the interview were informed of their status an average of 5 months prior to the interview (range--1 to 13 months). Since questions about mental health and current sexual behavior focused on the 12 months prior to the interview only a portion of the measured time period includes the time that these men knew their antibody status. Thus, the ability to detect differences due to knowledge of antibody status is diminished here because of our inability to separate time periods during which antibody status was known from the time period during which antibody status was not known. However, any significant differences that do emerge may be taken as suggestive of areas in which knowledge of antibody status will have an impact within a relatively brief time period.

The three groups were compared on the following three mental health measures: (1) demoralization, a measure which taps nonspecific psychological distress and depressive symptomatology, (2) subjective sense of vulnerability to contracting AIDS, and (3) AIDS-specific distress symptoms including intrusive and avoidant thoughts about AIDS, panic attacks, thoughts of death, and dreams and nightmares about AIDS. No significant difference among the three groups was found on demoralization. However, significant differences were found on measures of subjective vulnerability and AIDS-specific distress. Men who knew that they were antibody-positive report more intense feelings of vulnerability ($p < .04$) and more intense

distress symptoms ($p < .02$) compared to men who knew they were antibody-negative and men who were unaware of their antibody status. The last two groups do not differ from each other on either measure.

Comparisons among the three groups on measures of sexual behavior revealed no significant differences in number of partners, frequency of engaging in specific sexual activities, or tendency towards condom use. As noted above, the lack of differences associated with knowledge of antibody status may be due to methodological factors, and thus cannot be relied upon at this time.

In summary, these results suggest that within the New York City gay community men who are close to someone who is sick with AIDS and who have relatively good psychological defenses against the threat of AIDS will be the most likely men to seek testing. The issue of confidentiality of test results is the most frequent reason for avoiding testing followed by concern for one's ability to cope with the stress of anticipating the test result and dealing with the issues raised by it. The majority of those seeking their antibody status indicate that a positive result would not lead to behavioral changes since relevant changes have already been made, particularly with regard to sexual behavior. However, a substantial minority claims that they would change their behavior, given a positive result, and the main change would be towards more caution in sexual activity. Preliminary empirical results indicate that knowledge that one is antibody-positive leads to increased feelings of vulnerability to developing AIDS and increased psychological distress symptoms associated with this AIDS-related fear. Thus, while better psychological defenses characterize those who present for testing these defenses may be broken down by knowledge of being antibody-positive.

Log, Said to List AIDS Test-Takers, Is Lost

WASHINGTON, April 22 (AP) — Two city officials said today that a confidential log of people who underwent AIDS testing had vanished from a city health clinic.

Other officials, who declined to confirm a report that the book contained the names of 500 people tested for exposure to the AIDS virus, said the volumn had been missing since last Friday.

The police and health officials said they were not able to say the book had been stolen. They said there was a chance it had been misplaced or accidentally thrown out.

The Public Health Commissioner, Dr. Reed Tuckson, said he would not identify the contents of the book, but two city officials close to the investigation, who spoke on condition of anonymity, asserted that it contained the names of people who had tests for the AIDS virus performed through the clinic.

Prosecution Is Threatened

Public health officials warned that disclosing information about the book's contents was a Federal offense and insisted that anyone attempting to use the list would be prosecuted.

"Our goal right now is to retrieve the book and prevent anything like this from ever happening again," Dr. Tuckson said.

Although security at the clinic, the Alcohol and Drug Abuse Services Administration, has been tightened, Dr. Tuckson said reports of the apparent lapse would frighten people from being tested for acquired immune deficiency syndrome.

AIDS is a fatal disease that attacks the body's immune system, rendering it incapable of resisting other diseases and infections. No cure has yet been found.

The Washington Times quoted unidentified sources as saying the list included 500 names.

"We don't know what's happened to this book," said Steve Smith, chairman of the Metropolitan Washington Committee on AIDS Issues. "We can only hope it doesn't, hope it hasn't, fallen into the hands of someone who will want to harass or intimidate the people whose names are included."

Disappearance Has Raised Fear

The Metropolitan Police Department's Internal Affairs Division, which normally investigates crimes involving city employees, is handling the search for the book.

Mr. Smith said the disappearance had raised fears among those who have used the clinic and now "are imagining the variety of consequences."

"Inevitably, blackmail is a theoretical possibility," said a city Department of Human Services spokesman, Charles Seigel. "But that's purely theoretical, because it's got information that could be used for blackmail."

The Washington Times also quoted sources as saying that two clinic officials had been suspended without pay while the investigation is conducted. Dr. Tuckson declined to comment on the report, but he insisted that despite the lapse, the city's medical records were under good security.

Steps to Protect Confidentiality

"Steps have been taken and were taken to protect confidentiality," Dr. Tuckson said. "I am satisfied that security is now what it ought to be."

He continued, "My recommendation always has been that people should come in for voluntary, anonymous testing. We don't want to know their names. There is no need for us to know these people's names."

Armed guards are stationed on each floor of the three-story clinic, and visitors must sign in to enter. At the central reception desk, which has a separate entrance, one receptionist sits in the middle of a busy waiting room and screens all visitors.

City/suburbs

Rumors raise havoc with AIDS testing programs

By Jean Latz Griffin

The possibility of mandatory reporting of those who test positive for the AIDS virus is playing havoc with testing programs in Chicago as some people rush to get tested and beat the deadline while others fail to keep their appointments because they are afraid their names will be revealed.

Increasing numbers of people are calling for appointments, often saying they want the test while it is still anonymous, say operators of city and private clinics.

At the same time, the "no show" rates at the clinics have climbed steeply as people skip their appointments, erroneously thinking that the bills are law and that their names will be reported if they undergo the tests.

Bills requiring mandatory reporting of those who test positive, as well as of those who have the disease, await Gov. Thompson's signature or veto. He says he will act on the legislation in September.

Officials at Howard Brown Memorial Clinic say confusion over the legislation is hurting its research activities by scaring people away from joining groups to track the epidemic and causing national health agencies to doubt the clinic's ability to protect the anonymity of patients in ongoing studies.

"It depends on what rumor is going around at the time," said Patrick Lanahan, spokesman for the Chicago Health Department. "If people hear the bills will become law, they try to beat the deadline. If the word goes out that somehow their names are already being reported, they fail to show up."

The number of appointments scheduled at the city's two test sites rose by 20 percent in both May and June. But the "no show" rate rose to 46 percent in June from 41 percent in May and 34 percent in April, according to the health department. No figures are available for July.

Howard Brown reports the same pattern. "Our no-show rate is up, but at the same time people are scrambling to be tested before mandatory reporting," said Dan Dever, spokesman for the North Side clinic, which provides medical care and counseling for anyone with a sexually transmitted disease, including AIDS.

Cancellations at Howard Brown jumped to 39.4 percent in July from 28 percent in June. The clinic tests about 300 people a month.

"And last Saturday [Aug. 1], a full 56 percent of those who were scheduled to be tested did not show up for their appointments," said Reuben Dworsky, clinic director.

The legislation would require doctors and clinics to report the names of infected and sick people to the Illinois Department of Public Health. The health department would then try to trace the sex partners of those people, though there would be no penalty if they refused to divulge names.

Supporters of the legislation say it is necessary to know how many people in Illinois are infected to stem the epidemic. But opponents say it will have the opposite effect by driving people away from testing.

Dworsky says that if anonymous testing is eliminated, "our board of directors will have to decide whether we can continue testing. It is our policy that testing must be voluntary, it must be accompanied by counseling and it must be anonymous."

He said concern about the legislation "is already hurting us in following the natural history of the disease."

"We are trying to get a group of black gay and bisexual men together to monitor infection rates and the epidemic," Dworsky said. "People are hesitant to join because they fear their names might be reported."

A major national health agency recently expressed concern to Howard Brown that the clinic would not be able to maintain the anonymity of patients in a research project.

Officials of the clinic say they reassured the agency that a local law would not affect the research contract because of a federal confidentiality exemption.

Dworsky said that although it would not be possible to put all people tested at the clinic under that exemption, "we will explore every option to protect the anonymity of all our clients. Ethically, reporting names would put us in an unviable position."

AIDS, acquired immune deficiency syndrome, is thought to be caused by human immunodeficiency virus, or HIV. The test shows the presence of antibodies to the virus in the blood, thus indicating that the person has been exposed to HIV.

Scientists do not know how many infected people will get AIDS. The U.S. Public Health Service estimates that 20 to 30 percent of those infected and another 30 percent will develop symptoms of AIDS within that time, according to Chuck Fallis, spokesman for the Centers for Disease Control.

AIDS destroys the body's immune system, leaving it defenseless against numerous infections and cancers. As of Aug. 3, 39,594 cases had been diagnosed nationally and 22,747 people had died. The majority have been homosexual or bisexual men, intravenous drug users who share needles and people who have had sex with them.

The test at the city clinics is free and includes counseling and confirming tests if the first test is positive. The waiting time is three weeks at the city's southside clinic and seven weeks for the North Side clinic.

Howard Brown, which charges $56 for counseling, the initial test and any confirming tests, is now taking appointments for the middle of August. But because of the high cancellation rate, the clinic is also double-booking times at earlier

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Thieves Steal Computer Containing Confidential List of 60 AIDS Victims

By RICHARD C. PADDOCK, *Times Staff Writer*

SACRAMENTO—A confidential list containing the names of about 60 AIDS patients was stored in a computer stolen from the California AIDS office, officials said Wednesday.

Dr. Alex Kelter, acting deputy director of Public Health, said it would be "virtually impossible" for the thieves to enter the computer's memory and retrieve the names without knowing a computer password. All data collected by the state on these AIDS patients—as well as thousands of others who have the disease—remains confidential, he insisted.

"I am totally confident that this has not compromised anyone," Kelter said.

However, several AIDS experts outside state government expressed concern that the theft could undermine efforts to combat the disease. The promise of confidentiality for acquired immune deficiency syndrome patients is a central element in persuading potential AIDS carriers to have themselves tested for exposure to the virus, they said.

"If extremely sensitive information is going to be gathered about people, it has to be protected with the utmost care," said Bruce Decker, chairman of the California AIDS Advisory Committee. "When information that could deprive an individual of their job, home, family relations or friendships is not necessarily or adequately protected, then all citizens should be concerned."

The list of about 60 names was stored in the memory of one of three IBM computers stolen from the Sacramento AIDS office Sunday night or early Monday morning, Kelter said.

State police, who are investigating the theft, said they suspect that the burglars stole the computers in order to resell them and were not interested in

Please see LIST, Page 36

LIST: Names of AIDS Victims

Continued from Page 3

information about AIDS patients. Three other computer thefts from government offices have been reported in the area in recent months, a police spokeswoman said.

Under state law, county health officials must report AIDS cases to the state. Los Angeles and San Francisco counties, which account for more than 80% of all AIDS cases in California, provide the state with coded numbers, rather than the names of patients, when reporting AIDS cases. However, other counties give the state the names of AIDS patients, along with such data as whether they are homosexuals or intravenous drug users.

All three computers taken in the burglary were used to track the progress of the disease, but only one was used to store confidential information, Kelter said.

Under the AIDS office rules, the data should have been erased from the computer's memory long ago. However, when state experts reviewed a backup computer tape to see what information was taken in the burglary, Kelter said they found that a list of names and the characteristics of about 60 AIDS patients, dating back more than a year, had never been erased.

"It was intended to be totally purged," he acknowledged, "and a fragment remains on the disk."

Kelter said it is highly likely that immediately after the theft the burglars erased the entire memory of the computer to eliminate any identifying characteristics of the machine. But even if they had not, he said, the data identifying the AIDS patients was unlabeled, difficult to interpret and virtually inaccessible except to those who know the computer password.

Documents and files in the AIDS office were not taken in the burglary, Kelter said. Another computer containing detailed data on AIDS patients, which was stored in a more secure part of the office, was not stolen.

Dr. Don Francis, an AIDS specialist with the federal Centers for Disease Control, said the burglary highlights the need not only to maintain strict confidentiality but also to prevent discrimination against AIDS patients in the event that confidential information leaks out.

"Confidentiality is not absolute," Francis said. "If we're going to bring all these people in and encourage the infected people to come forth, then we have to protect them against inappropriate discrimination."

Last year, Gov. George Deukmejian vetoed legislation that would have protected AIDS patients from discrimination in housing and employment. The governor said the measure was not needed because AIDS patients are protected under existing laws.

Decker, the AIDS committee chairman, said the theft should serve as a reminder to lawmakers of the need for confidentiality. The Legislature is considering a bill that would weaken the strict privacy standards adopted two years ago.

"I would hope that this perhaps innocent burglary would cause those in favor of weakening that confidentiality some pause," he said.

Senate Bill #686

My name is Doctor Gordon Risk, and I'm the president of the American Civil Liberties Union of Kansas. I'm here today to register our comments and concerns regarding SB 686. Since I am a physician and psychiatrist I am also directly affected by this bill, and since I am appearing as an opponent of this bill I will begin with my criticism of it.

New Sec. 2(a) requires physicians to report the name and address of any person who has tested positive for HIV or who has AIDS to the secretary of health and environment. To obtain informed consent for the testing the responsible and ethical physician would have to inform his patient that a positive result would have to be reported to the secretary of health and environment, that the secretary would then undertake supervision of him, that the secretary might adopt and enforce rules and regulations with regard to his supervision as may be thought necessary, that the confidentiality of the information might be breached if the secretary decides that this is necessary to protect the public health, and that the secretary's powers could be delegated to county boards of health, who could then make use of the information as they best saw fit. Not to inform one's patient of these consequences would be to suborn the patient's consent for the testing and would be an abuse of him. Since all of the consequences for testing positive are negative, who will seek testing? Physicians who take seriously their oath to do their patients no harm would be forced to become law breakers.

Similarly, a physician would need to inform all patients that any information verbally reported to him indicating that an individual has tested positive for HIV or has AIDS would need to be reported to the secretary of health and environment. Although a superficial assessment of New Sec. 2(a) would suggest that hearsay information is excluded, it in fact is not. "Information indicating that a person has tested positive for HIV or is suffering from or has died from AIDS shall be reported;" e.g., if someone tells his physician that he understands that his neighbor has AIDS or is infected with HIV, the physician would have to obtain the name and address of that individual and report this information to the secretary if he is not to be guilty of breaking the law. This section encourages malicious reporting and has the potential of causing much harm. I would suspect that individuals with the disease and those with the infection who may develop the disease would be less apt to seek counseling for their condition if reporting to the state is the only certain result. Without counseling affected individuals may be in a poor position to deal with their feelings and to act in a thoughtful manner.

All this of course is prologue to the central sections of this bill, which give the secretary of health and environment the power to undo, alter, or augment anything the legislature may decide with regard to AIDS or the virus that causes it. New Section 3(a) permits the secretary to "adopt and enforce rules and regulations for the prevention and control of HIV and AIDS and for such other matters relating to cases of persons who have tested positive for HIV or who have AIDS as may be necessary to protect the public health." For those of us concerned with individual liberty, this grant of power is a Trojan horse.

The secretary may decide that funeral directors will be informed of the deceased's AIDS status, even though this legislature may have decided otherwise. He may decide that physicians "shall" inform other treatment personnel about a patient's AIDS status, even though this legislature may have decided otherwise. He may order contact tracing or pre-marital testing, measures rejected by this legislature. Quarantine could be ordered. Since his authority may be delegated to county boards of health, they would presumably have the power to "adopt and enforce rules and regulations" as they saw fit, and to make their own determinations as to whether confidentiality should be breached. The exception allowing breach of confidentiality, "if the disclosure is necessary, and only to the extent necessary," is an exception so large as to render the concept of confidentiality meaningless. The path is clear for many to be damaged.

If this bill is adopted the secretary of health and environment and county boards of health can do whatever they want as long as it can be rationalized as related to AIDS, without regard to individual rights and liberties or due process. There would be no significant constraint upon their ability to interfere in the life of the citizens of this state in whatever way they might wish. This is a wholly inappropriate grant of power, quite at odds with our ideas of limited government and individual rights. Adoption of this provision would be an abdication by the legislature of its responsibility to draw up laws narrowly crafted to achieve a specific purpose, with attention to harmful consequences.

I think that New Section 4 should read that a physician "may" disclose HIV information "to other health care personnel who because of the involvement with the care of the patient are subject to risk of exposure to HIV." This offers the patient greater protection of his right to privacy than the requirement that the physician "shall" disclose such information and is to be preferred on this account. Other health care personnel who think the physician has exercised his discretion improperly can sue for damages.

Testing sex offenders offers no real assistance to the victim, who must proceed in a timely way to look after his or her own mental and physical health. The victim can't wait for the trial, conviction, and testing of the offender to act. Testing of the offender would constitute an unreasonable search and seizure under the Fourth Amendment and would be a violation of the offenders' right to privacy. We should not be guilty of violating the right to privacy of sex offenders simply because they have been guilty of violating the rights of others. The bill paradoxically may leave the victim of a sex offence less likely to seek and utilize help through HIV testing, since a positive result would place him or her under the preview of the secretary of health and environment, who would have power "to enforce rules and regulations for the prevention and control of HIV and AIDS." This result would be doubly unjust.

The provisions of this bill providing for anonymous testing and mandatory reporting are in conflict with one another and reflect, I believe, the absence of a coherent approach. AIDS is not casually transmitted. Except for perinatal transmission from mother to fetus, it requires two consenting individuals, who have sex or share a needle. It can best be contained if individuals at risk or actually infected alter their behavior.

Individuals should be encouraged to get testing for HIV and be able to get counseling, as needed, to deal with their emotions and behavior. To this end the discovery of one's HIV status should be made as painless as possible. Any law that would leave one vulnerable to scrutiny and deprivation of civil liberties, if one tests positive for the virus, will discourage individuals from finding out their status. This is bad public health policy. As the Center for Disease Control notes: "Public health prevention policy to reduce the transmission of HIV infection can be furthered by an expanded program of counseling and testing for HIV antibody, but the extent to which these programs are successful depends on the level of participation. Persons are more likely to participate in counseling and testing programs if they believe that they will not experience negative consequences in areas such as employment, school admission, housing, and medical services should they test positive. There is no known medical reason to avoid an infected person in these and ordinary social situtations since the cumulative evidence is strong that HIV infection is not spread through casual contact. It is essential to the success of counseling and testing programs that persons who are tested for HIV are not subjected to inappropriate discrimination." Anonymous testing and counseling would be most helpful in this regard, together with legislation prohibiting discrimination on the basis of HIV status or presence of the disease. These messures would encourage individuals to test themselves and would be most helpful in combating the spread of the disease.

H

TO: The Kansas House Federal and State Affairs Committee

I address you-all with respect, as when I worked in the Senate in the "good old days"--the only life and death we had on the agenda was abortion and the ever-present death penalty bills. You and Congress must deal with a plague that could find Kansas with 420,000 cases by the year 1900. With those figures, it can't be pushed behind windfalls and school finance, etc. If not addressed in many ways, we won't be worrying about those mundane matters--too many will be dying/not paying taxes--and fewer will live to raise children to attend our schools.

My background, other than working for Senators Bennett and Warren, working in The Western Kansas Governor's Office, for attorneys for 20+ years, a period Earl Brookover called my "saving souls years" as a preacher's wife--now to what he called my "saving lives period"--my agencies (five of them) say in Garden City, America, that "one stop does it all." We do home health, hospice, healthy start, buckle-up-baby, private duty nursing, sitting and companion work, and we now own an equipment company. If a person's needs cannot be met through an agency requiring reimbursement (Medicare/Medicaid/BC-BS), we have personnel who work the extra hours to care for those with no resources; we have donated equipment that can be used by those who cannot pay; we also became trained to be an independent testing center for AIDS testing. My partner and I pay most of the wages there; at least one and a half hour of pre and after counselling is required.

We have cared for until their deaths only four patients at this time; we have four more in progress; three are on AZT and the fourth will be. None are presently homebound/bedbound or horribly sick like they will be. We have found they need understanding and friends who are not afraid more than they need anything. I brought with me an interview given by one of our patients--he's a wonderful young man; I enjoy his company--he wants work and has done some volunteer work for us; he works with and benefits from a small support group we started. Dr. Wade was amazed at our group success but "Michael" says it is successful because outsiders don't interfere--there is no social worker facilitator (we couldn't afford one); their MASH nurse came to the first one which lasted only three hours--she didn't come to the second one and they were together until 4 a.m. We could find no community facility, however, to house their meetings...so they do meet at our office!

Attach H.

Another issue that was accepted quickly by my old Legislature was the ERA--a matter of equal rights--non-discrimination...actually the questions of abortion by choice and the death penalth are discrimination bills, too, matters of freedom to make a personal choice. By passing laws, you must not take away personal freedom; you must educate all to what is acceptable in a democracy. They have the choice to accept or to not accept--and go to a crowded prison - ha!

SB 686 does attempt to protect the rights of persons with AIDS by granting them a dose of confidentiality; it would aid those who have had their bodies violated in that it would offer them testing and counselling at the state's expense, but it doesn't protect my right or your right to be made aware of the fact that someone we've been in intimate contact with has AIDS. Would you think about that while I tell you some of my experiences/feelings about AIDS?

Confidentiality is a great concern--because people are ostracized -- by their families, their churches, their employers, etc. This bill gives them confidentiality -- unless they get a test for AIDS from their physician. 99 out of 100 persons who think they "might" won't go to a physician...they'll come to my office where we advertise confidentiality. Let me just tell you about two cases...

One was one of my very best friends--she went to give her quarterly pint of blood at the Red Cross, and to volunteer hours at the bloodmobile. They took her blood; they had for years...and after testing called my office and asked if we could locate this person. Red Cross does get names and addresses...they aren't covered by the rules. My partner did contact her, tested her again, her husband, her children and her newborn grandson...all negative except for her. She went to Wichita for further testing--she has AIDS--she is now getting AZT and dying. But, her confidentiality was violated somewhere. She and her family got threatening calls and harrassment until they left town. The second case was one of a real question of law...to tell or not to tell. A mother brought in her three children; they had been sexually abused by her "live-in-friend" who discovered after the abuse that he had AIDS. Which law prevails--do we maintain confidentiality??? Or are we mandated to report him for child abuse???

Your SB 686 would have physicians report names and physicians would have those names and addresses. MOST HIGH RISK PERSONS do not go to their physician for this test; they go to a confidential testing site. It's not their old lovers they want it kept from; it's their parents, their employer, those whose understanding must be asked for, those they must tell themselves...and those they can never tell.

We now have only one nurse who gives the test; when we start getting paid by the State to do the tests, we will get others trained. There are a few people in Garden City who have said they wanted the test, but didn't want to come to Karen. A couple of months ago I was asked to close the door to my office; a person wishing the test didn't want me to know. I don't know whether it was my husband, my son, my minister, etc., but whoever it was, I am glad they came for the test. If it was someone who could have transmitted the disease to me -- I feel sure had they been positive, they would have come to me to get tested, but of course, I already have been.

We have tested many -- I don't know how many; Karen may know them personally, but usually doesn't; each one gets a number and gives a name. We do not have phone numbers, addresses, or full names. There are other questions asked--age, sex, high risk reasons, etc. and those are all noted for posterity--so we know numbers. Releases are signed for drawing of the blood, etc. This is probably not something that could/should be legislated, but I feel <u>sure</u>--absolutely positive, that those people would strongly consider signing their name at the same time to a promise to give us names of anyone they might have infected if they in fact test HIV positive...and/or after a second and third test when there was NO doubt.

We would make it a crime to knowingly infect someone after discovery of the virus; not premeditated murder exactly, BUT if that is a crime, wouldn't refusing to give names of others who could have the virus--be a kind of involuntary manslaughter???

We're not dealing with killers or even criminals. We're dealing with people who are dying because they have loved or because they found ordinary living wasn't a "big enough high"--[redacted]

You are protecting one's person's confidentiality and disregarding dozens of friends the right to plan the remainder of their life--if they have contacted the virus. IF you want to be a good "big brother," and protect your constituents--why not mandate testing for EVERYBODY? I remember lining up at school for the TB vaccine--I don't think I had a choice; all children have to have their vaccines before entering school. IF an AIDS vaccine is found, will you or Congress mandate vaccination?

If you can put a seat belt on me--for my safety--I don't know why you can't give me a test--or let me know I should get one!

The man who knew he could have infected innocent children took the chance of jail--in order for their mother to know they should be tested. Persons taking the test sign a release for the drawing of blood. I maintain they would also promise to let us contact potential victims of this plague, and/or would do it themselves...if they test positive through the initial test and the others that end the hope that the first one was a "false positive."

Even if we did not "force test" all those who could have been exposed, we should give the current patient the opportunity to have someone else advise their old friends...It would remain up to them when to tell their parents, their employers, etc.

I promised Linda this wouldn't be long, but I just can't put my feelings about not only my patients' right for confidentiality, but everyone's "right to know" -- in a nutshell. Perhaps this session should have made its main focus "AIDS"--without definitive action SOON, we won't need to worry about the future.

I believe my experience in the field--with patients and their families--gives me an awareness of WHO has AIDS, what common, loving human beings they are...how they would feel about saving their confidentiality vs. saving lives of others. I thank you for your time and if you have questions, I would be glad to try to answer them.

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An additional page that has nothing to do with this legislation...

I've said I do have a hospice/home health agency...AIDS patients may have the good fortune to have a family or other strong care-givers...and they may not. The end products of AIDS are horrible; the bravest of families may not be able to face it.

They do NOT belong in a nursing home, or a hospital...they belong together, helping each other. MASH started a "support group" that has worked better than others around the state...a MASH nurse attended the first one, and it lasted two or three hours. She left them alone for the next one and it ended about 4 a.m. Even in our small area, there are several with AIDS. A facilitator isn't even needed; they just need each other...

I would ask for a measure that would not only be cost-effective for the state (as most patients will end up on Medicaid) but would be humanitarian for the victims and their families. My agency, or other agencies, could set up a "hospice-home" for those persons; they could come whenever they wish--early so they could help with the care of others, or late so they could be cared for by MASH nurses/aides/volunteers. Medicaid could then cut out a lot of the individualized medical care--give food stamps to feed them and general assistance to pay their "rent" at the hospice...with the round-the-clock nursing being the major expense.

It's something to think about...something I would like to help set up.

JACQUE SUE-SWEARINGEN
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P.S. I'm one of those people who is living by "grace"; my heart stopped twice March 10, 1980. I believe I was given my life back for a purpose...to help "the least of His children"--and I am.