Approved: 3-31-99
Date

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE.

The meeting was called to order by Chairperson Sandy Praeger at 10:00 a.m. on March 17, 1999 in Room 526-S of the Capitol.

All members were present except:

Committee staff present: Emalene Correll, Legislative Research Department
Norman Furse, Revisor of Statutes
JoAnn Bunten, Committee Secretary

Conferees appearing before the committee:
Amy Sherbenou, Health Services, Cessna Aircraft, Wichita
Larry Wilkinson, M.D., Medical Director, Cessna Aircraft
Bud Burke, Cessna Aircraft
Bob Williams, Kansas Pharmacy Association
Larry Froelich, Executive Director, Board of Pharmacy
Sally Finney, Kansas Public Health Association
Don Carrel, K.C., AIDS educator
Gianfranco Pezzino, M.D., Kansas Department of Health & Environment
Eddie Lorenzo, K.C., ACLU

Others attending: See attached list

Hearing on: SB 350 - Sale of non-prescription medicines and drugs through vending machines

Amy Sherbenou, Supervisor for Health Services at Cessna Aircraft Company, testified before the Committee in support of **SB 350** which, if enacted would clarify that only non-prescription drugs could be sold through vending machines. Ms. Sherbenou noted that many employers, including Cessna Aircraft Company, have dispensed over-the-counter medications to their employees for years. This practice is not required, but it has provided employees relief from minor discomforts and allowed individuals to continue working. She felt that the sale of non-prescription medication through a vending machine in a climate-controlled area would be beneficial to both employees and employers. (Attachment 1)

Also speaking in support of **SB 350** was Larry Wilkinson, Medical Director for Cessna. Dr. Wilkinson provided the Committee with written testimony from other aircraft companies in support of the bill. (Attachment 2)

Bob Williams, Executive Director of the Kansas Pharmacists Association, noted that his organization had opposed a similar bill last year, but have withdrawn that opposition since their concerns were addressed in paragraph (b) of **SB 350** having to do with outdated drugs and the location of vending machines. Mr. Williams informed the Committee that there still exists some issues that they may want to address, and they are: (1) If a retailer sells 12 or more non-prescription drug products in a vending machine, they would be required to obtain a permit from the Board, and the State Board of Pharmacy would be required to inspect the vending machines annually; and (2) the bill does not place any restrictions on what type of non-prescription drug products may be sold through vending machines as noted in his written testimony. (Attachment 3)

Larry Froelich, Executive Director, State Board of Pharmacy, also expressed some concerns with the bill, and suggested the Committee may want to add additional language that would restrict each machine to less than 12 items; that a non-prescription drug cannot include a controlled substance, poison or an injectable product; and each vending machine that contains non-prescription drugs must have an obvious and legible statement on the machine that identifies the owner of the machine, a toll-free number that the consumer can notify the owner, advises the customer to check the expiration date of the product before using, and lists the phone number of the Board of Pharmacy. (Attachment 4)

Bud Burke, representing Cessna Aircraft Company, expressed his support for **SB 350**, and was asked by the Chair to work with the Revisor, Board of Pharmacy and Kansas Pharmacists Association to amend the bill in order to address the concerns expressed by the two conferees and report back to the Committee.

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE, Room 526-S, Statehouse, at 10:00 a.m. on March 17, 1999.

Hearing on: HB 2074 - HIV and AIDS monitoring

Sally Finney, Executive Director, Kansas Public Health Association, testified before the Committee in support of **HB 2074**. The proposed legislation would allow name-based HIV reporting in Kansas. It would require any laboratory director in the state to report within 30 days any confirmed HIV infection. Ms. Finney noted that HIV case reporting would help to assure that infected individuals are linked to the public health system to receive information about treatment options and available resources to support care, strengthen the public health system's ability to reach out to individuals who may have been exposed to infected persons through high-risk behavior, and significantly improve the state's ability to monitor the spread of HIV into various populations. (Attachment 5)

Speaking in opposition to the bill was Don Carrel, AIDS educator, who told the Committee that he is HIV infected. Mr. Carrel outlined three concerns he has with the bill which are as follows: names reporting would prevent some people from being tested, a need to increase the penalty for breach of confidentiality, and too much power exists with the Secretary of Health and Environment to adopt and enforce rules and regulation for the prevention and control of HIV infection or AIDS. (Attachment 6)

Gianfranco Pezzino, M.D., State Epidemiologist, KDHE, testified in support of the bill. Dr. Pezzino noted that the main objectives of a name-based, confidential HIV reporting system are to describe current patterns of HIV infection and transmission, to assure that HIV infected individuals are referred for proper case management which would include counseling and anti-HIV therapy, and to assure confidential partner notification of sexual partners of HIV infected individuals following a well established and successful model sued for other sexually transmitted diseased. (Attachment 7)

Speaking in opposition to **HB 2074** was Eddie M. Lorenzo, Legal Director for the American Civil Liberties Union. Mr. Lorenzo cited three reasons the ACLU opposes the bill: First, evidence shows that name reporting discourages people from being tested for HIV; second, no reliable safeguards exist, legal or otherwise, which would ensure the privacy of those who test positive for HIV, and which would protect them from discrimination; and third, alternative methods for HIV tracking exist which do not require name reporting. (Attachment 8)

Written testimony was submitted in support of the bill by Jerry Slaughter, KMS, who noted that by passing **HB 2074**, the legislature would help to ensure that federal funding for HIV and AIDS programs continues. Mr. Slaughter also pointed out that the bill would also allow KDHE to gather more comprehensive data on the incidence and prevalence of HIV and AIDS patients in Kansas. Confidentiality of sensitive information collected through names reported was also stressed. (Attachment 9)

The Chair requested that KDHE provide information to the Committee on the issue of federal funding as it relates to name reporting, how to provide strict confidentiality, and how many physicians treat people infected with HIV.

Adjournment

The meeting was adjourned at 11:00 a.m.

The next meeting is scheduled for March 18, 1999.

Unless specifically noted, the individual remarks recorded herein have not been transcribed verbatim. Individual remarks as reported herein have not been submitted to the individuals appearing before the committee for editing or corrections.

SENATE PUBLIC HEALTH AND WELFARE COMMITTEE
GUEST LIST

DATE: 3-17-99

NAME	REPRESENTING
Stacey Soldan	Hein & Weir
Roxanne Davis	Cessna
Amy Sherbenou	Cessna
Larry Wilkinson	Cessna
Barb Clancy	Jo Co. Commission on Aging
Norge Jerome	" " " "
Susan Duran	Issues Management Group
Alexis Stevens	A.C.L.U
Eddie M. Lorenzo	ACLU of Kansas & W. Missouri
DON CARREL	K.C. AIDS EDUCATOR AND A PWA
Bob Williams	Ks Pharmacists Assoc.
Bob Anderson	KS PHARMACISTS ASSOC.
KEITH R LANDIS	CHRISTIAN SCIENCE COMMITTEE ON PUBLICATION FOR KANSAS
Darlene Stearns	League of Women Voters
LARRY FROELICH	Ks Bd of PHARMACY
Roger Hersh	McLouth KS
Bob Nikesic	Lawrence KS
Gianfranco Pezzino	KDHE
LORNE PHILLIPS	KDHE

SENATE PUBLIC HEALTH AND WELFARE COMMITTEE
GUEST LIST

DATE: 3-17-99

NAME	REPRESENTING
Rich Guthrie	Health Midwest
Tonya Buckloffs	WU Student
Pat Hayes	KDHE LAB
Stephen N. Paige	KDHE
Sally Finney	Ks. Public Health Assn.
Joe L. Lund	KDHE
Karl Milhon	KDHE
Ryan Gaddert	KCCI
Bud Burke	Cessna Aircraft Co.
[illegible]	KHN

TESTIMONY
SENATE BILL 350
MARCH 17, 1999

MY NAME IS AMY SHERBENOU. I AM THE SUPERVISOR FOR HEALTH SERVICES AT THE CESSNA AIRCRAFT COMPANY. THANK YOU FOR PROVIDING ME WITH THE OPPORTUNITY TO ADDRESS THE COMMITTEE ON HOUSE BILL 2538.

MANY EMPLOYERS, INCLUDING THE CESSNA AIRCRAFT COMPANY, HAVE DISPENSED OVER-THE-COUNTER MEDICATIONS TO THEIR EMPLOYEES FOR YEARS. THIS PRACTICE IS NOT REQUIRED OF US BUT IT HAS PROVIDED EMPLOYEES RELIEF FROM MINOR DISCOMFORTS AND ALLOWED INDIVIDUALS TO CONTINUE WORKING. USED AS DIRECTED, OVER-THE-COUNTER MEDICATIONS ARE SAFE AND EFFECTIVE. THE SALE OF THEM THROUGH A VENDING MACHINE IN A CLIMATE-CONTROLLED AREA POSES NO SAFETY RISK IF THE MEDICATION IS IN THE MANUFACTURER'S ORIGINAL, TAMPER-EVIDENT PACKAGE WHICH NOTES THE EXPIRATION DATE.

IN 1998, THROUGH COMPUTERIZATION OF HEALTH SERVICES DATA, CESSNA DISCOVERED INFORMATION REGARDING OUR DISTRIBUTION OF OVER-THE-COUNTER MEDICATIONS IN THE WORKPLACE. CESSNA'S WICHITA-BASED EMPLOYEES MADE 43,334 VISITS TO HEALTH SERVICES AND 21% OF THOSE VISITS WERE FOR OVER-THE-COUNTER MEDICATIONS. WHY IS THIS A CONCERN FOR INDUSTRY? ON AN AVERAGE, EACH EMPLOYEE AT

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OUR LARGE FACILITIES SPENDS A TOTAL OF 30 MINUTES WALKING TO A FIRST AID FACILTY, OBTAINING OVER-THE-COUNTER MEDICATION, AND WALKING BACK TO HIS OR HER WORKSTATION. THE IMPACT OF THIS ON PRODUCTION IS DRAMATIC WHEN WE CONSIDER THE EMPLOYEES' SALARIES AND THE LOSS OF PRODUCTION TIME. THE 9,191 VISITS MADE TO HEALTH SERVICES IN 1998 FOR OVER-THE-COUNTER MEDICATIONS ALONE COST OUR COMPANY APPROXIMATELY $300,000. AS OUR COMPANY CONTINUES TO GROW, THESE COSTS WILL ESCALATE.

CESSNA EXPERIENCED A SIMILAR CIRCUMSTANCE IN 1998 WITH FREQUENT REQUESTS FOR BLOOD PRESSURE CHECKS. IN THE FIRST SIX MONTHS OF THAT YEAR, WE LOST THOUSANDS OF HOURS OF PRODUCTION DUE TO EMPLOYEE VISITS TO HEALTH SERVICES SOLELY FOR BLOOD PRESSURE CHECKS. WE THEN DECIDED TO PLACE BLOOD PRESSURE MACHINES IN THE CAFETERIAS WHERE THEY WERE EASILY ACCESSIBLE TO EMPLOYEES ON THEIR BREAKS AND AT LUNCH. THE IMPACT WAS SIGNIFICANT. THE LAST SIX MONTHS OF 1998 REVEALED A 70% DECREASE IN REQUESTS FOR BLOOD PRESSURE CHECKS AT THE HEALTH SERVICES STATIONS WHICH RESULTED IN MEANINGFUL COST SAVINGS. WE BELIEVE THAT PROPER UTILIZATION OF VENDING MACHINES FOR OVER-THE-COUNTER MEDICATIONS WILL HAVE A SIMILAR IMPACT.

WHEN WE PUT BLOOD PRESSURE MACHINES IN OUR CAFETERIAS, EMPLOYEES LOST NO MEDICAL ATTENTION; IT WAS JUST RECEIVED DIFFERENTLY. THIS WILL ALSO BE THE CASE IF

DISPENSING OVER-THE-COUNTER MEDICATIONS THROUGH VENDING MACHINES WOULD BECOME LAWFUL.

CESSNA IS IN THE BUSINESS OF MAKING AIRPLANES, HOWEVER, WE ARE ALSO COMMITTED TO ADDRESSING THE NEEDS OF OUR EMPLOYEES. WE BELIEVE THAT THE PASSAGE OF HOUSE BILL 2538 WOULD ALLOW A SAFE AND CONVENIENT WAY OF PROVIDING OVER-THE-COUNTER MEDICATIONS IN AN INDUSTRIAL ENVIRONMENT WHICH WOULD BE BENEFICIAL TO BOTH EMPLOYEES AND EMPLOYERS.

ALTHOUGH CHILDREN AND ADULTS ALIKE CAN READILY PURCHASE THESE PRODUCTS IN THE LOCAL GROCERY STORES, ONLY KANSAS, ARIZONA, AND GEORGIA STILL PROHIBIT THE SALE OF OVER-THE-COUNTER MEDICATIONS IN VENDING MACHINES. WE RESPECTFULLY REQUEST THAT THIS LEGISLATION BE PASSED SO THAT WE WILL NO LONGER BE ONE OF A VERY FEW STATES THAT PENALIZES EMPLOYERS FOR ASSISTING THEIR EMPLOYEES WITH CONDITIONS THAT CAN BE TREATED BY OVER-THE-COUNTER MEDICATION.

TESTIMONY
SENATE BILL 350
MARCH 17, 1999

MY NAME IS DR. LARRY WILKINSON. I AM THE CONTRACT MEDICAL DIRECTOR FOR THE CESSNA AIRCRAFT COMPANY, AND PRESIDENT OF PRO-MED PHYSICIAN SERVICES, A COMPANY THAT PROVIDES ON-SITE OCCUPATIONAL MEDICAL STAFFING SERVICES.

HISTORICAL PERSPECTIVE

- Only three states (Arizona, Georgia & Kansas) restrict OTC (over-the-counter) vending machines.
- Many Fortune 500 companies utilize OTC vending machines (IBM, Xerox, AT & T, 3M, Sam's Club and Sony).
- Significant testimony during 1998 to pass a new bill.

MEDICAL CONSIDERATIONS

- OTC medications are designed for self limiting minor illness/injury.
- Decreases occupational nurses time dealing with minor health care issues.
- Increases occupational nurses time to provide care to significant health care issues.
- Reduces medical liability for standing orders regarding dispensing medication.
- Increases medication compliance (unit dose).
- Reduces medication hoarding (unit dose).

SPECIAL CONSIDERATIONS

Are childproof containers necessary?

No — OTC vending machine medications come in unit dose, tamper proof containers.

Is a climate controlled environment necessary?

No — Utilization and turnover of OTC medications is high, therefore, any stability issues or shorter expiration dates are not a concern.

SUMMARY

Vending machines for OTC medications provides an accessible, safe and convenient avenue for business and industry.

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Learjet Inc.

8220 West Harry Street, Wichita, KS 67209-2942
P.O. Box 7707, Wichita, KS 67277-7707
Phone (316) 946-2000

March 13, 1999

Dear Gary Boston
Health & Human Services Committee,

I am writing to you in regards to Bill #2538 that is on the agenda for Wednesday, March 17, 1999. I am a registered nurse at Bombardier Aerospace Learjet in the Occupation Health Department in Wichita, Kansas. We would like the Health & Human Services Committee to review and pass Bill #2538 - Sale of medicines and drugs through vending machines.

Our facility currently supplies over the counter medications at the request of the employee. Approximately 75-85% of the requests are for non work related injuries or illness. This is very costly, especially during the cold and flu seasons. It is also very time consuming passing out over the counter medications all day. We would like to install a vending machine and stock it with the basic over the counter unit dose medications such as Aspirin, Tylenol, Ibuprofen, and Maalox. Passing this Bill would benefit our company by allowing the employees to choose their own medications, thus placing the liability on themselves. It would also give them some responsibility in taking care of their own health problems that are not work related.

Thank you for introducing this Bill today. We hope that this Bill will be passed today by the Health & Human Services Committee.

Thank you for your consideration.
Sincerely,

Karen

Karen Lehman R.N.
Occupation Health Nurse
Bombardier Aerospace Learjet

Raytheon Aircraft Company
9709 E. Central
P.O. Box 85
Wichita, KS 67201-0085

Raytheon Aircraft

Beech
Hawker

March 15, 1999

Dr. Wilkinson
c/o Cessna Health Service
PO Box 7704
Wichita, KS 67277

RE: Non-Prescription Medication Vending Machines

I feel that non-prescription medication vending machines would be of significant advantage to our operations with little down-side risk.

I have observed this type machine in numerous manufacturing facilities outside Kansas. When queried, the managers at these plants speak highly of the process and report no adverse problems.

Recommend that Kansas law be changed to allow such operations.

Sincerely,

Robert, C. Hutchison, Manager
Safety and Industrial Hygiene

2-3

THE KANSAS PHARMACISTS ASSOCIATION
1308 SW 10TH AVENUE
TOPEKA, KANSAS 66604-1299
PHONE (785) 232-0439
FAX (785) 232-3764

ROBERT R. (BOB) WILLIAMS, M.S., C.A.E.
EXECUTIVE DIRECTOR

TESTIMONY
Senate Committee on Public Health and Welfare
March 17, 1999

Senate Bill 350

My name is Bob Williams, I am the Executive Director of the Kansas Pharmacists Association. Thank you for this opportunity to address the Committee on SB 350.

As many of you know, last year we opposed a similar bill which also allowed for the sell of over-the-counter medications through vending machines. While the Kansas Pharmacists Association continues to believe it is poor public policy to allow medications to be sold in vending machines which are easily accessible by children, we have withdrawn our opposition. We are pleased to note that some of our concerns have been addressed in paragraph (b) having to do with outdated drugs and the location of vending machines. However, there continues to be some issues which the Committee may want to address.

KSA 65-1643 states that any person operating a store or place of business to sell, offer for sale or distribute any drugs to the public, must register or obtain a retailer's permit from the State Board of Pharmacy. An exemption is allowed in paragraph (f) if the retail dealer sells 12 or fewer different nonprescription drug products. I have attached a copy of KSA 65-1643 for your review. Presumably, according to KSA 65-1643, if a retailer sells 12 or more nonprescription drug products in a vending machine, they would be required to first obtain a permit from the board. Additionally, the State Board of Pharmacy would be required to inspect the vending

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machines annually as they do other retail dealers. Retailer permits are $12 annually, renewed February 1. If the Committee does not feel it necessary to require a retailer's permit, you may want to consider restricting the sell of nonprescription drug products to 12 or fewer items when sold through a vending machine.

In addition, SB 350 does not place any restrictions on what type of nonprescription drug products may be sold through vending machines. As many of you know, for the past couple of years the Attorney General of Kansas has been seeking passage of a "Chemical Control Act". HB 2469 has been introduced and hearings conducted in the House Judiciary Committee. One of the many aspects of this legislation is to restrict the sell of ephedrine, pseudoephedrine and phenylpropoanolamine containing products such as Sudafed, Tylenol Cold and Sinus, Contac and Nyquil to name a few. These common nonprescription medications can be used in the illegal manufacturing of drugs in so called "meth labs". The Committee may wish to restrict the sell through vending machines of these highly potent nonprescription drugs.

Thank you.

name, strength and quantity of the drug dispensed and the name of the dispensing pharmacist; and (D) drug allergies and sensitivities.

(2) Upon receipt of a prescription order, the pharmacist shall examine the patient's medication profile record before dispensing the medication to determine the possibility of a harmful drug interaction or reaction to the medication. Upon recognizing a potential harmful drug interaction or reaction to the medication, the pharmacist shall take appropriate action to avoid or minimize the problem which shall, if necessary, include consultation with the prescriber with documentation of actions taken on the prescription record.

(3) A medication profile record shall be maintained for a period of not less than five years from the date of the last entry in the records.

(4) All prescription drug orders communicated by way of electronic transmission shall conform to federal and state laws and the provisions of the board's rules and regulations.

(e) No registration shall be issued or continued for the conduct of a pharmacy until or unless the provisions of this section have been complied with.

History: L. 1953, ch. 290, § 28; L. 1975, ch. 319, § 28; L. 1982, ch. 262, § 2; L. 1986, ch. 235, § 4; L. 1987, ch. 236, § 4; L. 1989, ch. 194, § 1; L. 1994, ch. 254, § 5; L. 1997 supp., ch. 112, § 2; July 1.

65-1643. Registration or permit required; pharmacies, manufacturers, wholesalers, auctions, sales, distribution or dispensing of samples, retailers, institutional drug rooms; certain acts declared unlawful. On and after the effective date of this act, it shall be unlawful:

(a) For any person to operate, maintain, open or establish any pharmacy within this state without first having obtained a registration from the board. Each application for registration of a pharmacy shall indicate the person or persons desiring the registration, including the pharmacist in charge, as well as the location, including the street name and number, and such other information as may be required by the board to establish the identity and exact location of the pharmacy. The issuance of a registration for any pharmacy shall also have the effect of permitting such pharmacy to operate as a retail dealer without requiring such pharmacy to obtain a retail dealer's permit. On evidence satisfactory to the board: (1) That the pharmacy for which the registration is sought will be conducted in full compliance with the law and the rules and regulations of the board; (2) that the location and appointments of the pharmacy are such that it can be operated and maintained without endangering the public health or safety; (3) that the pharmacy will be under the supervision of a pharmacist, a registration shall be issued to such persons as the board shall deem qualified to conduct such a pharmacy.

(b) For any person to manufacture within this state any drugs except under the personal and immediate supervision of a pharmacist or such other person or persons as may be approved by the board after an investigation and a determination by the board that such person or persons is qualified by scientific or technical training or experience to perform such duties of supervision as may be necessary to protect the public health and safety; and no person shall manufacture any such drugs without first obtaining a registration so to do from the board. Such registration shall be subject to such rules and regulations with respect to requirements, sanitation and equipment, as the board may from time to time adopt for the protection of public health and safety.

(c) For any person to distribute at wholesale any drugs without first obtaining a registration so to do from the board.

(d) For any person to sell or offer for sale at public auction or private sale in a place where public auctions are conducted, any drugs without first having obtained a registration from the board so to do, and it shall be necessary to obtain the permission of the board in every instance where any of the products covered by this section are to be sold or offered for sale.

(e) For any person to in any manner distribute or dispense samples of any drugs without first having obtained a permit from the board so to do, and it shall be necessary to obtain permission from the board in every instance where the samples are to be distributed or dispensed. Nothing in this subsection shall be held to regulate or in any manner interfere with the furnishing of samples of drugs to duly licensed practitioners, to pharmacists or to medical care facilities.

(f) Except as otherwise provided in this subsection (f), for any person operating a store or place of business to sell, offer for sale or distribute any drugs to the public without first having obtained a registration or permit from the board authorizing such person so to do. No retail dealer who sells 12 or fewer different nonprescription drug products shall be required to obtain a retail dealer's permit under the pharmacy act of the state of Kansas or to pay a retail dealer new permit or permit renewal fee under such act. It shall be lawful for a retail dealer who is the holder of a valid retail dealer's permit issued by the board or for a retail dealer who sells 12 or fewer different nonprescription drug products to sell and distribute nonprescription drugs which are prepackaged, fully prepared by the manufacturer or distributor for use by the consumer and labeled in accordance with the requirements of the state and federal food, drug and cosmetic acts. Such nonprescription drugs shall not include: (1) A controlled substance; (2) a drug product the label of which is required to bear substantially the statement: "Caution: Federal law prohibits dispensing without prescription"; or (3) a drug product intended for human use by hypodermic injection; but such a retail dealer shall not be authorized to display any of the words listed in subsection (u) of K.S.A. 65-1626 and amendments thereto, for the designation of a pharmacy or drugstore.

(g) For any person to sell any drugs manufactured and sold only in the state of Kansas, unless the label and directions on such drugs shall first have been approved by the board.

(h) For any person to operate an institutional drug room without first having obtained a registration to do so from the board. Such registration shall be subject to the provisions of K.S.A. 65-1637a and amendments thereto and any rules and regulations adopted pursuant thereto.

Kansas State Board of Pharmacy

LANDON STATE OFFICE BUILDING
900 S.W. JACKSON STREET, ROOM 513
TOPEKA, KANSAS 66612-1231
PHONE (785) 296-4056
FAX (785) 296-8420

STATE OF KANSAS

EXECUTIVE DIRECTOR
LARRY FROELICH

BILL GRAVES
GOVERNOR

1999 KANSAS LEGISLATIVE SESSION
SENATE BILL No. 350
Senate Committee on Public Health and Welfare

Senator Sandy Praeger, Chairperson
Committee Members

SB 350 has concerns that the Board of Pharmacy believes need to be addressed:

Currently, K.S.A. 65-1643(f) requires: "No retail dealer who sells 12 or fewer different nonprescription drug products shall be required to obtain a retail dealer's permit under the pharmacy act of the state of Kansas or to pay a retail dealer new permit or permit renewal fee under such act. It shall be lawful for a retail dealer who is the holder of a valid retail dealer's permit issued by the board or for a retail dealer who sells 12 or fewer different nonprescription drug products to sell and distribute nonprescription drugs which are prepackaged, fully prepared by the manufacturer or distributor for use by the consumer and labeled in accordance with the requirements of the state and federal food, drug and cosmetic acts."

The definition of Retail dealer is found in K.S.A. 65-1626(ff): "**Retail dealer**" means a person selling at retail nonprescription drugs which are prepackaged, fully prepared by the manufacturer or distributor for use by the consumer and labeled in accordance with the requirements of the state and federal food, drug and cosmetic acts. Such nonprescription drugs shall not include:

(l) A controlled substance;

(2) a drug the label of which is required to bear substantially the statement "Caution: Federal law prohibits dispensing without prescription; or

(3) a drug intended for human use by hypodermic injection.

The Board of Pharmacy currently has **2,009** retail dealer permits. The retail dealers are annually inspected. The annual fee is **$12.00**. If the vending machine contains more than 12 items, then a retail dealers permit should be required. The bill does not mention a quantity limit of items. I would like to suggest **additional language to restrict each machine to less than 12 items.**

Ephedrine is a nonprescription controlled substance. Although ephedrine is a <u>schedule V controlled substance</u>, it is **<u>not</u>** a prescription drug (K.S.A. 65-4113) and may be sold through these vending machines. The definition of nonprescription drug is not within this bill and not within the pharmacy practice act. I would suggest that

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the committee consider language that **references that a nonprescription drug cannot include a controlled substance, a poison or an injectable product.**

I have included examples of inspection reports for retail dealers that show where outdated merchandise was found. I believe no one intentionally tries to sell outdated merchandise, but it does happen and that is a potential problem to the consumer. I propose that the bill contain language to require **the owner to check the machines monthly and record the inspections to protect from selling outdated items.**

There is no mention of the locations of these machines to allow for monitoring of the items for sale. If the locations are identified, how are they inspected? If the consumer has concerns with the products, are toll-free numbers listed for the consumer to contact the owner? In regards to liability of ingestion of outdated products, who assumes the liability? If inspected, are the owners identified on the machine for responsibility of the guilty party? Last year, I proposed adding language **"Each vending machine that contains nonprescription drugs must have an obvious and legible statement on the machine that identifies the owner of the machine, a toll-free number that the consumer can notify the owner, advises the customer to check the expiration date of the product before using, and lists the phone number of the Board of Pharmacy."**

Finally, the committee heard testimony last year that Kansas and Arizona are the only two states that still prohibit vending machine sales. I have attached **examples of other States prohibiting** this procedure.

KANSAS STATE BOARD OF PHARMACY
INSPECTION OF RETAIL DEALERS

Name: [redacted]

Street: 245 E [redacted] Street

City: [redacted] Zip: 67216

County: SG

Original Permit No. 36609

Renewal No. They did not return — will now — $24.00

Type of Business: Supermarket ✓ Dept. Store ___ Restaurant ___ Family Center ___ Grocery ___ Convenience Shop ___

Other: ___

AREAS OF INSPECTION:

Drugs (Household): Halls, Ludens, Epsom Salt, H_2O_2, Alcohol, Vaseline, Mineral Oil,

Injectable for Human Use: ___

Expiration Dates Checked: Tinactin, Mycelex OTC, Micatin, Aftate, Afrin, Triaminic, Vicks 44E, 44M, Dexatrim-1, Cortaid, Caldecort, Actifed, Sudafed, Dimetapp, Motrin IB, Advil, Pepto Bismol, Kaopectate, Mycitracin,

+ dates

REMARKS: Bayer Extra Strength 10/97, Bayer Low strength 5/98, Bayer Low Safety Coated 6/97, Bayer Caplets 2/98, Advil Cold & Sinus 1/97, Tylenol Caplets 11/97 (3), 12/97 (2), 5/97 (1), 9/97 (1), Benadryl Gel 2/98

Talked with manager. Many outdates — will recheck in ≈ 6 months. (Person not rotating stock)

Drug Wholesaler: ___

Signature of Operator on Duty: Gene [redacted] Date: 4-21-98

Signature of Inspector: C. Hergren RPh

Address all correspondence and request for information to: Kansas State Board of Pharmacy
Landon State Office Building
900 Jackson, Room 513
Topeka, KS 66612-1220
(913) 296-4056

KANSAS STATE BOARD OF PHARMACY
INSPECTION OF RETAIL DEALERS

Name: [redacted] #20

Street: [redacted] E 21st

City: [redacted] Zip: 67208

County: Sg

Original Permit No. 34564

Renewal No. 97-98

Type of Business:

Supermarket	✓	Family Center	
Dept. Store		Grocery	
Restaurant		Convenience Shop	

Other:

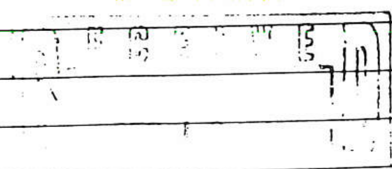
AREAS OF INSPECTION:

Drugs (Household): Witch Hazel, Petroleum Jelly, H_2O_2, Alcohol, Epsom salt, Calamine, Cod Liver Oil, Sweet Oil, Castor Oil, Boric Acid, Halls, Ludens, Chapsticks, Blistex

Injectable for Human Use:

Expiration Dates Checked: Midol, Pamprin, Cortisone 10, Oxy 10, Mycelex 7, Vagistat 1, Lotrimin AF, Tinactin, Sensitive Eyes, Renu, Visine, Dramamine, Maalox, Mylanta, Pepcid AC, Tagamet HB, Zantac 75, Motrin IB, Advil, Tavist 1

REMARKS: Micatin Powder 12-95, 3-97, Aug 93, Micatin Spray 12-96 & 4, 97
Lotrimin AF Spray Powder 2, 97, Desenex 6-96



Drug Wholesaler:

Signature of Operator on Duty: [signature] Date: 12-1-97

Signature of Inspector: Carly Haggan R.Ph.

Address all correspondence and request for information to: Kansas State Board of Pharmacy
Landon State Office Building
900 Jackson, Room 513
Topeka, KS 66612-1220
(913) 296-4056

4-A

KANSAS STATE BOARD OF PHARMACY
INSPECTION OF RETAIL DEALERS

Name: [redacted] Mart

Street: 1018 E 4th

City: [redacted] Zip: 67330

County: LB

Original Permit No. 38448

Renewal No. 98-99

Type of Business:

Supermarket		Family Center	
Dept. Store		Grocery	✓
Restaurant		Convenience Shop	

Other:

AREAS OF INSPECTION:

Drugs (Household): Holly Ladera Alcohol, H_2O_2, Witch Hazel Calamine,

Injectable for Human Use:

Expiration Dates Checked: Rapid Relief → Pain Reliever, Advanced Pain Reliever, Ex-Pain, Complete Allergy Stay Alert, Antacid Relief, Rolaids, Tums, Mylanta, Pepcid AC, Imodium AD, Pepto Bismol, Tylenol ES, Tylenol Drops, Doans, Midol PMS, Ex-Lax Contac, Tylenol Flu, Benadryl, Vicks Sinex, Robitussin, Dramamine, Sucrets,

REMARKS:

* Out dated Maalox Tablets 12/98 : 1/99, Actron 4/98 Dristan Cold's Caugh, Afrin 8/98, Dimetapp 10/98

Drug Wholesaler:

Signature of Operator on Duty: [signature]

Date: 2-23-99

Signature of Inspector: C. Hagner RPh

Address all correspondence and request for information to: Kansas State Board of Pharmacy
Landon State Office Building
900 Jackson, Room 513
Topeka, KS 66612-1220
(913) 296-4056

4-5

KANSAS STATE BOARD OF PHARMACY
INSPECTION OF RETAIL DEALERS

Name: [redacted] Discount
Street: 3108 W. [redacted]
City: [redacted] Zip: 67203
County: SG

Original Permit No. 36882
Renewal No. 97-98

Type of Business: Supermarket ____ Dept. Store ____ Restaurant ____ Family Center ✓ Grocery ____ Convenience Shop ____
Other: ____

AREAS OF INSPECTION:

Drugs (Household): Carmex, Blistex, Chapstick, Alcohol, H2O2, Epsom Salt, Witch Hazel, Vaseline, Halls, Ludens

Injectable for Human Use: ____

Expiration Dates Checked: Sine-Aid, Tylenol Sinus, Tylenol Cold, Dristan KT, FemStat 3, Correctol, Desenex, Lotrimin AF, Micatin, Opcon A, Bronchoflex, Robitussin DM, CF, PE, Metamucil

REMARKS: Arthritis Foundation (5) 5-97, (3) 7-97, Vicks 44M Pediatric (1) Sep 97, Advil (1) 10/97, Sucrets 8-95, Sucrets 2-97 lots

* Comment will be back to verify outdates have been pulled. - Verify by spot checking

Drug Wholesaler: ____

DEC 1 1997

Signature of Operator on Duty: [signature]
Date: 12-3-97

Signature of Inspector: C. Hagman RPh

Address all correspondence and request for information to: Kansas State Board of Pharmacy
Landon State Office Building
900 Jackson, Room 513
Topeka, KS 66612-1220
(913) 296-4056

4-6

KANSAS STATE BOARD OF PHARMACY
INSPECTION OF RETAIL DEALERS

Name: [redacted] #41

Street: 2445 [redacted]

City: [redacted] Zip: 67217

County: SG

Original Permit No.: 3 7[illegible]

Renewal No.: 98-99

Type of Business: Supermarket ✓ | Dept. Store ___ | Restaurant ___ | Family Center ___ | Grocery ___ | Convenience Shop ___

Other: ___

AREAS OF INSPECTION:

Drugs (Household): Alcohol, H_2O_2, Calamine, Halls, Ludens, Mineral Oil, Chapstick, Blistex, Witch Hazel, Glycerin, Sweet Oil, Vaseline, Epsom Salt,

Injectable for Human Use: ___

Expiration Dates Checked: Oxy 10, Caladryl, Visine, Ocuhist, Naphcon A, Desenex, Flintstones, Centrum, Midol, Pamprin, Axid AR, Claritin, Dimenhydrinate, Phillips Chewable, Alka-Seltzer PM, Kaopectate, Maalox Anti Gas, Tempra, Afrin, Comtrex, Coricidin D, Sucrets, Dristan, Bayer, Aleve, Orudis KT, Motrin IB

REMARKS:

Outdated Viractin 4/98 Cream, 5/98 Gel, Benadryl Gel 11/98, Boston Rewetting Drops 8/98, Actifed 3/96, Allerest 11/98

Drug Wholesaler: ___

Signature of Operator on Duty: S. [redacted] Date: 12-11-98

Signature of Inspector: C. Haggren RPh

Address all correspondence and request for information to: Kansas State Board of Pharmacy
Landon State Office Building
900 Jackson, Room 513
Topeka, KS 66612-1220
(913) 296-4056

4-7

KANSAS STATE BOARD OF PHARMACY
INSPECTION OF RETAIL DEALERS

[redacted] Store

Name: [redacted], LLC

Street: ~~6th F~~ 601 [redacted] Street

City: [redacted] Zip: 66064

County: MI

Original Permit No. 38651

Renewal No. 98-99

Type of Business:

Supermarket	______	Family Center	✓
Dept. Store	______	Grocery	______
Restaurant	______	Convenience Shop	______

Other: ______

AREAS OF INSPECTION:

Drugs (Household): Alcohol, Calamine, Epsom Salt, Petroleum Jelly, Halls, Blistex

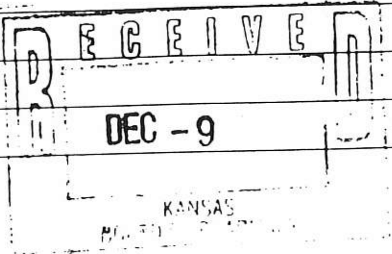
Injectable for Human Use: ______

Expiration Dates Checked: Infant Glycerin Suppositories, Rogaine, Vit E 200 IU, ShurFine Bismuth Tablets, Eckerd Pink Bismuth, HEB Relief Cap, Stop&Shop Tussin, Pathadryl, DayHist I, CVS Cold & Cough, Treasury Backache, Mylanta AR, TopCare Nasal Spray, Tylenol Jr., Triple Antibiotic, Caladryl for Kids,

REMARKS:

outside
Outdated: Allefrin 2/98, Bausch & Lomb Sensitive Eyes 8/98, Lactaid 8/98
Arbor Gum Relief Soft gel 6/98, Vit A 8000 IU 5/98
Minoxidil Topical Sol. 2% Vitamin C 250 mg 10/98

Drug Wholesaler: ______



Signature of Operator on Duty: [signature] Date: 12-2-98

Signature of Inspector: C. [signature] R.Ph.

Address all correspondence and request for information to: Kansas State Board of Pharmacy
Landon State Office Building
900 Jackson, Room 513
Topeka, KS 66612-1220
(913) 296-4056

KANSAS STATE BOARD OF PHARMACY
INSPECTION OF RETAIL DEALERS

Name: [redacted]   Original Permit No. 10-37137

Street: 121 N. [redacted]   Renewal No.

City: [redacted] Zip: 67467

County: Ottowa

Type of Business:

Supermarket		Family Center	
Dept. Store		Grocery	
Restaurant		Convenience Shop	X

Other:

AREAS OF INSPECTION:

Drugs (Household): Tylenol, Children Tylenol, Nyquil, Advil, Excedrin, Excedrin, Aleve, allerest, contac, Actifed, Mylanta, Maalox, Dimetapp, Visine

Injectable for Human Use: —

Expiration Dates Checked: Yes

REMARKS:
- Alka-Seltzer Plus cold (1X2) Exp 4/98
- Anacin (2X30) Exp: 7/98 and 1/98
- Preparation H oint (2X28) Exp 10/97

Drug Wholesaler: Lamone

Signature of Operator on Duty: [signature, partially redacted]   Date: 11-25-98

Signature of Inspector: [signature], R. Ph.

Address all correspondence and request for information to: Kansas State Board of Pharmacy
Landon State Office Building
900 Jackson, Room 513
Topeka, KS 66612-1220
(913) 296-4056

4-9

KANSAS STATE BOARD OF PHARMACY
INSPECTION OF RETAIL DEALERS

Name: [redacted] Market

Street: 312 S [redacted]

City: [redacted] Zip: 67335

County: MG

Original Permit No. 34709

Renewal No. 98-99

Type of Business:

Supermarket		Family Center	
Dept. Store		Grocery	
Restaurant		Convenience Shop	✓

Other:

AREAS OF INSPECTION:

Drugs (Household): Calamine, Alcohol, H_2O_2, Hills, Ludens, Epsom Salt, Boric Acid Powder

Injectable for Human Use:

Expiration Dates Checked: Drixoral, Contac, Benadryl, Sucrets, Sudafed, Alka-Seltzer Plus Cold, Robitussin, Robitussin Maximum Strength, Midol, Gas-X, Ex-Lax, Pepto Bismol tablet, Imodium AD

REMARKS:

outdated Nytol 7/98, Kaopectate 9/96, Kaopectate 1-D 3/96, Phillips MOM 9/96, Rolaids

Drug Wholesaler:

Signature of Operator on Duty: Phyllis M. [redacted] Date: 11-19-98

Signature of Inspector: C. Hagmeier RPh

Address all correspondence and request for information to: Kansas State Board of Pharmacy
Landon State Office Building
900 Jackson, Room 513
Topeka, KS 66612-1220
(913) 296-4056

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WEST VIRGINIA

WV BReg 15-1-2.
Definitions.

The following words and phrases as used in this Rule have the following meanings, unless the context otherwise requires:

2.1. The term "Drug" means

(a) substances recognized as drugs in the official "United States Pharmacopoeia, Official Homeopathic Pharmacopoeia of the United States, or Official National Formulary," or any supplement to any of them;

(b) substances intended for use in the diagnosis, cure, mitigation, treatment, or prevention of disease in man or animals;

(c) substances (other than food) intended to affect the structure of any function of the body of man or animals; and

(d) substances intended for use as a component of any article specified in subdivisions (a), (b) or (c) of this subsection. It does not include devices or their components, parts or accessories.

WV BReg 15-1-16.
Sale of Drugs by Mechanical Devices; Sharing Compensation.

16.1. **The sale of drugs and medicines by mechanical devices or vending machines are prohibited.**

16.2. Sharing compensation.

The independent judgment of a pharmacist is a public trust, and his first allegiance is to the patient whom he or she serves. No pharmacist shall, except with a person licensed to practice pharmacy, or in the course of his or her employment with a duly licensed institution, clinic or foundation, directly or indirectly share compensation arising out of or incidental to his or her professional employment with, or accept professional employment from any person or persons who for compensation prescribe drugs used in the compounding or dispensing prescriptions.

GEORGIA

GA PracAct 26-4-2.
Definitions.

As used in this chapter, the term:

(1) ......

(7) "Drug" or "drugs" means:

(A) Articles recognized or for which the standards of specifications are prescribed in the official compendium;

(B) Articles intended for use in the diagnosis, cure, mitigation, treatment, or prevention of disease in man or other animals;

(C) Articles other than food, intended to affect the structure or any function of the body of man or other animals; or

(D) Articles intended for use as a component of any article specified in subparagraph (A), (B), or (C) of this paragraph, but does not include devices.

GA PracAct 26-4-8.
Penalty for dispensing drugs by vending machines.

Any person who shall sell or dispense drugs by the use of vending machines shall be guilty of a misdemeanor.

(Ga. L. 1956, p. 724, 2; Code 1933, 79A-9904, enacted by Ga. L. 1967, p. 296, 1.)

CONNECTICUT

CT BReg Sec. 20-175-44.
Sale of patent or proprietary medicinal compounds in vending machines

No patent or proprietary medicinal compounds, preparations or units put up in sealed or unsealed containers, labeled and accompanied with directions for use with the name and address of the manufacturer or distributor thereof, shall be sold or offered or exposed for sale or dispensed by any means in any type of vending machines.

MAINE

ME PracAct 13792.
Sale by certain methods prohibited

It shall be unlawful for any person to sell, distribute, vend or otherwise dispose of any drug, medicine or pharmaceutical or medical preparation by means of any public exhibition, entertainment, performance, carnival or by vending machines.

KS BReg 68-11-2.

[illegible]es for premises registrations and permits.

(a) Pharmacy registration and permit fees shall be as follows.

(1) Each new pharmacy registration shall be $140.00;

(2) Each renewal pharmacy registration shall be $125.00.

(b) Manufacturer registration and permit fees shall be as follows.

(1) Each new manufacturer registration shall be $300.00;

(2) Each renewal manufacturer registration shall be $300.00.

(c) Wholesaler registration and permit fees shall be as follows.

(1) Each new wholesaler registration shall be $300.00;

(2) Each renewal wholesaler registration shall be $300.00.

(3) Each wholesaler who deals exclusively in nonprescription drugs and for which no registration is required under the uniform controlled substances act there shall be a fee of $50.00.

(d) Institutional drug room registration and permit fees shall be as follows.

(1) Each new institutional drug room registration shall be $25.00;

(2) Each renewal institutional drug room registration shall be $20.00.

(e) Other registration and permit fees shall be as follows.

(1) For each retail dealer selling more than 12 different nonprescription drug products there shall be a permit fee of $12.00;

(2) Each auction permit shall be $35.00;

(3) Each sample distribution permit shall be $30.00.

(Authorized by and implementing K.S.A. 65-1645 as amended by L. 1987, ch. 236, Sec. 5; effective May 1, 1983; amended May 1, 1988; amended June 6, 1994.)

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KANSAS PUBLIC HEALTH ASSOCIATION, INC.

KANSAS PUBLIC HEALTH ASSOCIATION, INC.
AFFILIATED WITH THE AMERICAN PUBLIC HEALTH ASSOCIATION
215 S.E. 8TH AVENUE
TOPEKA, KANSAS 66603-3906
PHONE: 785-233-3103 FAX: 785-233-3439
E-MAIL: kpha@networksplus.net

Testimony on HB 2074
Presented by Sally Finney, Executive Director
on March 17, 1999

I am here to speak in favor of HB 2074, a bill changing the State's current reporting systems for cases of Human Immunodeficiency Virus (HIV) infection to include patient names.

The Kansas Public Health Association supports this legislation because of the benefits we believe it will create. Specifically, named HIV case reporting will help to achieve the following:

- **Assure that infected individuals are linked to the public health system to receive information about treatment options and available resources to support care.** The treatment of HIV disease has become a highly-specialized area of medicine. It is impossible for every primary care provider to understand its intricacies and about the various state and local resources available to persons living with HIV disease. Patients receive inconsistent, sometimes inaccurate information about their treatment options and may not know for years after diagnosis about the various support services that exist. Adding names to case reports submitted to KDHE will help to assure that HIV-positive Kansans receive more timely information about their care options.

- **Strengthen the public health system's ability to reach out to individuals who may have been exposed to infected persons through high-risk behavior.** HIV-infected Kansans diagnosed at public health counseling and testing sites are offered the option of working with trained professionals who can assist them in counseling sexual and needle-sharing partners who may have been exposed to the virus. This is done anonymously, without disclosure of any names, and is public health's best tool for providing personalized counseling to help at-risk persons reduce further risk of infection. Unfortunately, the vast majority of HIV-infected Kansans diagnosed through private care providers are rarely offered this service. There is no way of knowing how many Kansans have been exposed to HIV and who are unaware of that exposure. Providing names with HIV infection case reports will allow public health in Kansas to increase the availability of partner counseling throughout the state.

- **Significantly improve the State's ability to monitor the spread of HIV into various populations.** We know that infected individuals sometimes test twice at different sites for various reasons. Yet, there is no reliable way to eliminate these duplicate case reports from

Senate Public Health & Welfare
Date: 3-17-99
Attachment No. 5

the data. The resulting data set is one that the Centers for Disease Control and Prevention, the Council of State and Territorial Epidemiologists, and other consider unusable for purposes of tracking the course of the epidemic. Because the average incubation period for the onset of AIDS after infection with HIV is eight to ten years, AIDS case information tells us what happened in the last decade but tells us nothing about current trends. Adding names will give KDHE a data set that it can use to monitor trends in the virus' spread and will allow the State and local organizations to better plan targeted prevention and care programs.

One myth about the impact of implementing a name-based reporting system is that people will refuse to be tested. Reviews of testing numbers conducted in areas that have implemented named HIV reporting show that numbers may drop temporarily but usually rebound within a few months. To accommodate the few who might refuse to be tested in Kansas with this change, HB 2074 includes a provision allowing KDHE to designate sites to conduct anonymous testing. KPHA supports this provision.

HIV infection is the only reportable disease in Kansas where names are excluded from reports. Case reports for AIDS and all other reportable diseases include names. KDHE has a long history of safeguarding sensitive information, and KPHA is confident in the agency's commitment to continuing that tradition. Because KPHA values confidentiality of public health records, we strongly support the provisions of HB 2074 that increase penalties for breeches of confidentiality.

KPHA believes that HB 2074 will mean better care for persons with HIV infection, improved access to partner counseling services, and reliable information for public health to plan prevention and care programs. We ask your support for this legislation.

Thank you.

March 8, 1999

Senator Sandy Praeger
Chair of the Senate Health and Welfare Committee
300 SW 10th Avenue
Topeka, KS 66612

Re: HB 2074 – HIV Names Reporting Legislation

Dear Senator Praeger:

We are graduate students in the School of Social Welfare at the University of Kansas. Since HB 2074 was originally introduced in the House of Representatives, we have been doing research and attending committee meetings concerning this pending legislation.

Anonymous HIV testing is essential to ensure that people at risk for HIV disease are not deterred from being tested. We appreciate the fact the House version of this bill guarantees anonymous testing sites throughout the state. While we are encouraged by several of the changes the Health and Human Services Committee incorporated into this bill prior to passage in the House, we believe there are additional changes the Senate should consider.

According to the Centers for Disease Control, between 50 and 60 percent of HIV-positive Americans are unaware of their health status. Our first concern is that legislation not impede anyone from being tested for HIV. Mandatory names reporting will prevent some people from being tested. We are especially concerned about any plan that would permanently store the names of those who test HIV-positive in state records.

The Seattle/King County Board of Health has devised a plan that would allow the names of those infected with HIV to be reported to local health officials. The local health departments would then have 90 days to contact those infected for services and partner notification. After 90 days, the individual names would be converted into unique identifying codes for permanent storage in state records. We feel this compromise plan better assures long-term confidentiality and still allows local health departments adequate time to offer services to those infected with HIV.

A second concern regards the penalty for breach of confidentiality. While the House Committee did address this issue to some extent, we believe the penalty should be increased significantly to reflect the potential ramifications for individuals whose names might accidentally or intentionally be divulged by surveillance workers. There continues to be a stigma attached to those infected with HIV, and the possibility of discrimination toward those infected is real. Discrimination can lead to loss of employment, loss of health care benefits, social isolation, loss of housing and even acts of violence. Therefore, it is imperative we take the steps necessary to protect the civil liberties of HIV-infected individuals.

Texas recognizes the necessity of keeping HIV medical records confidential. Intentional or criminal negligent breaches of confidentiality result in a Class A misdemeanor. Surveillance workers who negligently release or disclose HIV information are liable for actual damages, a penalty of not more than $1,000, attorney fees and costs incurred in bringing the case to court. Workers who intentionally breach confidentiality are liable for

actual damages, a penalty of no less than $1,000 and no more than $5,000, attorney fees and any costs incurred in bringing the case to court. Kansas should consider similar penalties for a breach in confidentiality.

Finally, we are concerned with Section three (lines six through nine) which states "the Secretary may adopt and enforce rules and regulations for the prevention and control of HIV infection or AIDS as may be necessary to protect the public health." This section, as written, allows the Secretary of Health too much power. No individual should have the authority to establish rules and regulations affecting all those infected with any disease. We believe there should be a system of checks and balances in place to protect the civil liberties of those infected with HIV or any other disease.

Realizing the magnitude of the AIDS epidemic, we urge your attention to the matters we have discussed above. Following these guidelines could help ensure the privacy of medical records and hopefully would minimize the negative ramifications of HIV names reporting.

Enclosed are details on the King County Board of Health reporting recommendations, information on the penalty structure for breaches of confidentiality in the state of Texas and a copy of the testimony packet we previously submitted to the Health and Human Services committee in the House of Representatives.

Thank you for reviewing this information.

Sincerely,

Shellie Brandon
9990 College Blvd. #110
Overland Park, KS 66210

Donald K. Carrel
4839 Horton
Mission, KS 66202

Dana Crouch
6565 West Foxridge Drive
Mission, KS 66202

Shelby Markum
8701 Noland Road
Lenexa, KS 66215

C.C. Governor Bill Graves

Senators: Audrey Langworthy, Rich Becker, Laurie Bleeker, Janice Hardenburger, Sherman Jones, Janis Lee, Larry Salmans and Chris Steineger

HIV SURVEILLANCE MEDIA RELEASE

FOR IMMEDIATE RELEASE FOR INFORMATION CONTACT

January 15, 1999 media@nwaids.org

Response to King County HIV Surveillance Proposal

Foundation Applauds Added Protections

SEATTLE -- Officials at the Northwest AIDS Foundation today expressed optimism about the HIV surveillance plan adopted by the Seattle-King County Board of Health. Foundation representatives reiterated their support for a reporting system that did not involve the use of people's names, but asserted that facing political realities -- and the County's willingness to involve community-based organizations in drafting the recommendations -- makes the King County plan a viable option.

Said Foundation Executive Director Terry M. Stone, "The Northwest AIDS Foundation and the County Health Department had strong differences of opinion about how to best implement HIV surveillance, however, we had an even stronger commitment to create a system we could all support. The reality is that the State Board of Health is moving forward with a names-based reporting system. We worked hard on behalf of people affected by HIV and AIDS to erect a series of critical fire walls we believe will protect people who are HIV infected."

The King County plan is based on the recommendations of the Common Ground Task Force. Common Ground included representatives from the Northwest AIDS Foundation, the Seattle-King County Department of Public Health, the Governor's Advisory Council on HIV/AIDS, and the People of Color Against AIDS Network.

Foundation Director of Public Policy and Communications Steven B. Johnson stated, "The County's decision today is a victory for people living with HIV and AIDS. It reflects the partnership between affected communities and public health officials that the King County Board of Health and the Northwest AIDS Foundation feel is critical in stopping the spread of HIV. It is time for the State Board of Health to adopt the same level of collaborative partnership. Community cooperation is vital if a statewide HIV surveillance system is going to work."

The new King County surveillance system includes the following protections:

County Destroys Names After 90 Days: Names of people testing HIV-positive will be collected at the county level to allow for epidemiological tracking. The names will be destroyed after 90 days after being converted to a unique identifying code.

Names Not Reported to State: The County will use coded unique identifiers -- not names --

6-3

to forward HIV surveillance data to the Washington State Department of Health.

Access to Anonymous HIV Testing: Anonymous HIV testing will remain available throughout King County at public health facilities and community-based clinics.

Informed Consent for Partner Notification: People who test positive for HIV will have the option to either inform their sexual and needle-sharing partners about their HIV risk or request the assistance of Health Department staff.

Increased Penalties for Breaches of Confidentiality Recommended: The County will recommend to the State that breaches of confidentiality with malicious intent be increased from a misdemeanor to a felony.

Protections for People Who Have Already Tested Positive: People who have already tested positive for HIV will receive the same confidentiality protections as do people who test positive for the first time. Medical providers will not be required to submit names of their current HIV+ patients; those people will trigger standard case reports in the normal course of accessing care.

Testing Campaign: To enable people in all HIV-impacted communities to make informed choices about their HIV testing options, the Health Department and community will work together to identify resources and develop an educational HIV testing campaign.

Continued Executive Director Stone, "We hope these protections will help build trust in the system among people in affected communities. Public health officials are well aware that any HIV surveillance system will not succeed without the solid backing of people most impacted by HIV and AIDS."

Johnson voiced a commitment to ensuring that protections in the King County plan are enacted statewide. "We believe that this plan, while not perfect, provides added protections for people affected by HIV in King County. The Washington State Board of Health should adopt it as a template for developing a statewide HIV surveillance system. We will work with the Washington State Legislature to enact legislation to enhance the confidentiality protections for people living with HIV and AIDS statewide, and to include funding in the biennial budget for an enhanced testing outreach campaign."

Johnson also urged the federal Centers for Disease Control and Prevention (CDC) and other states that currently utilize names-based HIV reporting systems to institute these safeguards. "We hope that public health officials across the country will begin to take community concerns more seriously. This system will help minimize the deterrent effect of names reporting."

Currently, there are 2,216 people with AIDS living in King County, and 3,512 in Washington State. An estimated 13,500 people in Washington are HIV positive.

The Northwest AIDS Foundation is the largest AIDS Service Organization in the Pacific Northwest. NWAF provides direct care and emergency financial assistance to people living with HIV and AIDS; prevention education; public policy advocacy; and grants to other AIDS service organizations throughout Washington State.

6-4

Health news updated every weekday morning.

Seattle City Light
Value for our Customers.

Posted at 10:31 p.m. PST; Saturday, January 16, 1999

Reforms urged in reporting HIV cases

by Warren King
Seattle Times medical reporter

New cases of AIDS-virus infection should be reported to local health officials by name, but the names should be encoded when sent to state authorities, the King County Board of Health recommended yesterday.

The board voted 9-3 to recommend that state officials require local health departments to destroy the names after 90 days - or encode them if they are kept longer.

The resolution on how to establish a new tracking system was based on recommendations from a "common-ground group" of health officials and AIDS-organization representatives after more than three months of deliberation.

The state Board of Health, which will probably vote on a new reporting system in April, is likely to give strong consideration to the advice of Health Board members in King County, where the state's AIDS epidemic has been centered for more than 16 years.

Cases of AIDS (and 54 other infectious diseases) have always been reported by name to health authorities. But public-health officials and AIDS activists believe those newly infected by the AIDS virus, HIV, also should be reported because new drugs have dramatically increased survival times of many patients.

HIV reporting, including demographic information, would enable officials to better track the epidemic, offer early treatment to those infected and improve prevention efforts.

However, many AIDS activists question the government's ability to keep the names confidential and fear discrimination against those with HIV. They have urged reporting only by coded identifiers, saying name reporting would discourage

6-5

those at risk for HIV from being tested.

The King County board urged that anonymous testing continue to be allowed. Under its recommendation, a person could test anonymously and his or her name would be reported only when treatment was sought.

Among the board's other recommendations:

-- Increase the penalty for a breach of confidentiality to a felony.

-- Launch an extensive campaign to educate the public on whatever reporting system is adopted.

-- Clarify the language of the proposed state reporting rule.

-- Evaluate the coded system over time to ensure it meets performance standards set by the federal Centers for Disease Control and Prevention.

In addition, the board urged that public-health officials be required to obtain clear "informed" consent from infected individuals to notify any sexual partners that they might have been exposed to HIV. Contact with the infected patient should be made through the patient's physician, and the patient's identity must be protected in partner notification, the board said.

Representatives of the Northwest AIDS Foundation, a strong advocate of coded identifiers in reporting, said the resolution was "not perfect" but offered added measures for protecting names. But other AIDS activists blasted the name-reporting provision and vowed to urge that people be tested only anonymously.

"I feel like we've really been sold down the river," said Bill Lake of Positive Voice Washington, an organization of HIV-positive patients.

But health board Chairman Greg Nickels praised the resolution as an excellent compromise.

"I think this measure will protect confidentiality and also save lives," Nickels said.

Warren King's phone message number is 206-464-2247. His e-mail address is: wking@seattletimes.com

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Confidentiality and HIV Reporting by Name

Fact Sheet

- Surveillance information is not public information.

- By law, all surveillance information, including HIV reporting information, is *confidential* and *privileged.* The *Open Records Act, Medical Practice Act,* and the *Communicable Disease Prevention and Control Act* contain provisions which protect the confidentiality of disease reporting information. No one can find out a person's HIV status by filing an open records request or a Freedom of Information Act request.

- Surveillance workers cannot be subpoenaed or deposed to release surveillance information about an individual. Surveillance workers cannot be questioned in a civil, criminal, special or other proceeding about the existence or contents of surveillance records for a person who is examined or treated for a reportable disease without that person's consent (Health and Safety Code §81.046).

- Surveillance workers do not give law enforcement agencies, immigration agencies, the media, insurance companies, employers or families access to the databases which contain surveillance information. Health departments do not provide lists of names of people with HIV or AIDS.

- There are very limited circumstances under which surveillance information containing a name might be released. Surveillance workers can be ordered to release information on the HIV status of an individual to protect the health of a spouse (Health and Safety Code §81.107), health care workers (§81.107), first responders, emergency personnel, peace officers, fire fighters (§§81.048, 81.050), and victims of sexual assault (Code of Criminal Procedure).

- Surveillance workers who *negligently* release or disclose surveillance information are liable for:
  - actual damages
  - a penalty of not more than $1,000, and
  - the cost of bringing the case to court and attorney's fees.

- Surveillance workers who *intentionally* breach confidentiality are liable for:
  - actual damages
  - a penalty of not less than $1,000 and not more than $5,000, and
  - the cost of bringing the case to court and attorney's fees.

- Intentional or criminally negligent breaches of confidentiality are Class A misdemeanors.

- TDH employees who breach confidentiality are subject to disciplinary action up to and including termination.

- **Clients who believe their confidentiality has been breached should tell the director of the organization responsible for the breach. If the issue is not resolved or the client feels that it is inappropriate to discuss the breach with the organization's director, the client can call 1-800-299-AIDS to file a complaint with the TDH. Complaints can be filed anonymously.**

Testimony on HB 2074

Mandatory Names Reporting for HIV

Prepared by:

Don Carrel

Aids Educator

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Good afternoon. Thank you for taking the time to hear what I have to say regarding House Bill 2074. My name is Don Carrel, and I'm a person living with AIDS. I believe I was infected in 1982, but I suffered absolutely no symptoms for 13 years. In 1995, I developed pneumocystis pneumonia and was forced to close my business and retire.

After retiring, I started to knock on the doors of schools in Johnson County volunteering to talk to students about my life with AIDS. It wasn't easy. Initially, I received no support from school administrators, and I had to practically beg my way into a classroom. My persistence paid off. Once in the classroom, the student response was overwhelming, and teachers insisted I come back the following semester. I now speak each semester to more than 20 schools and colleges in the Kansas City area. In the last three years, I have helped approximately 20,000 Kansas teenagers and young adults learn that AIDS not only kills you, it destroys every aspect of your life in the process.

My 17 years of living with HIV disease and my AIDS education efforts make me more than qualified to express my opinion on any bill concerning HIV and AIDS and my disapproval of any law that requires HIV names reporting. My presentation to students always stresses the importance of HIV testing. In my professional opinion, there are two main reasons people do not get tested for HIV:

1. **They will not be tested for fear they must provide their name, address or phone number to the clinic doing the testing.**
2. **They simple do not believe they are at risk for HIV.**

Most research supports the fact that if names must be reported, many infected individuals choose not to get an HIV test. My education efforts have helped hundreds, and perhaps thousands, of students and young adults make the decision to be tested for HIV. With a fourth of all new infections occurring in those under age 19, and half in those under age 25, we cannot take any action that discourages teenagers and young adults from being tested for this virus. I have been told time after time, "Don, I **won't** get tested if I have to give out my name".

There is no doubt in my mind that if you require people, especially young people, to give out their name when tested, most will skip the test. Keeping their name a secret is so vital that almost all the teenagers I convince to be tested for HIV drive to a clinic away from their home communities because they are terrified they might be recognized.

Because of the level of existing stigma attached to HIV disease, it is essential for most people to keep their status confidential. This legislation does not guarantee the privacy of HIV records. Not only would one's identity be provided to the secretary of health and environment and his staff, it would also be provided to people working in HIV testing sites, health department personnel and anyone with the skills or knowledge needed to access these so called "confidential records."

Unfortunately, HIV discrimination still exists. Dr. Gregory M. Herek, a research psychologist at the University of California at Davis, is an international authority on discrimination against those with HIV disease. In a 1998 study, Dr. Herek reported that 17 percent of the public supports the quarantine of people

infected with HIV, 12 percent would avoid a co-worker with AIDS, and 33 percent would not shop at a store if they knew the owner had AIDS (Herek, 1998).

According to Section 3 of this bill, "The secretary may adopt and enforce rules and regulations for the prevention and control of HIV infection ... as may be necessary to protect the public health." What does this statement mean? Does it give such broad permission that I, as an HIV positive person, should fear being locked in quarantine, or be required to have HIV tattooed on my forehead because it might be necessary "to protect the public health?"

I am a graduate student at KU working on a Master's in Social Work. As a class project, we were asked to study legislation currently pending in Kansas. My group chose this bill. Last week we e-mailed every representative in the state asking for their views. One representative phoned me and expressed his personal concern that perhaps part of the reasoning behind this bill was to have a method to accumulate the names of HIV-positive people simply for "discriminatory purposes". This comment, coming from just one government official, scares me to death. It clearly indicates the potential risks for all infected with HIV.

As an MSW student, I have studied the policy statement of the National Association of Social Workers concerning HIV testing. The NASW believes:

> "HIV testing should be voluntary, confidential, and performed with informed consent. In addition, anonymous testing should be available, accessible, and free" (NASW, 1996).

In an effort to better track the AIDS epidemic, the Center for Disease Control and Prevention recommends states begin reporting HIV cases. This reporting can be done through the use of unique identifying codes. Tracking the prevalence of infection by the use of codes would be just as effective as tracking by name, yet would still guarantee those who are HIV-positive some protection. Reporting by code rather than by name, **never** discourages anyone from being tested.

In conclusion, I personally believe **every person in this country**, including all of you in this room, who are sexually active or using IV drugs should be tested for HIV. I will continue my personal efforts to convince young Americans at risk to be tested. However, if this bill passes, my job will be much more difficult.

As a man who has lived with HIV for nearly 17 years, and as the father of two sexually active sons in their early 20s, I am as motivated as anyone to bring AIDS under control.

Two weeks ago, I spoke at an AIDS conference in Kansas City with Kate Shindle. As Miss America in 1998, Kate devoted her year of public service to educating thousands of students about HIV. During her presentation, Kate expressed her frustration with many state and local restrictions that severely limited her ability to teach students what is needed to keep them alive. Many conservative politicians favor putting limits on AIDS education that hinder many of us from teaching teenagers how to stay healthy. I find it very ironic that many of the same politicians who wish to restrict HIV information to students are often the same politicians who most aggressively support HIV names reporting.

Expanded education for the public, especially our young, in conjunction with programs encouraging all Americans to get tested would immediately slow the spread of HIV. I believe in order to bring this disease to a halt, funds must be allocated for massive media campaigns to educate everyone about the dangers of HIV infection. Programs should also be funded that bring HIV testing to high schools and colleges, churches, places of employment and maybe even grocery stores. Anonymous testing should always be available, and it should always be free. If there had been a more aggressive government response to this plague 18 years ago, we would not be discussing this issue today.

Conclusion:

Please DO NOT PASS any legislation, which requires the reporting of names of those infected with HIV disease. There is significant data, which substantiates that:

- Many people who are at risk for HIV will choose not to be tested if required to provide their name. This fact is especially true for young Americans and gay men, who are two of the groups most at risk.

- Discrimination against those with HIV disease still exists. This legislation potentially puts those of us living with HIV in danger.

Instead, DO PASS legislation which tracks the prevalence of HIV disease through the use of unique identifying codes.

- This method of reporting will more accurately track the disease.

- This method will not discourage anyone from getting an HIV test.

- This method of reporting will help assure that discrimination against those with HIV disease will be less likely to occur.

In addition, to help bring this epidemic to a halt, please consider:

- Expanding the States emphasis on HIV education in schools.

- Implementing massive media campaigns designed to educate the general public to the fact that everyone could be at risk for HIV disease. And those at risk to need to get regular HIV screening.

- Allocating funds for HIV testing in high schools and colleges, churches, places of employment and even grocery stores.

I have included more detailed information concerning the above three suggestions in this report.

Thank you for taking the time to hear my testimony and review the attached information.

Don Carrel

References

CDC (Center for Disease Control) (1998). Trends in the HIV & AIDS Epidemic [Brochure]. US Government: Author.

Herek, G. (July 1, 1998). Nationwide Poll shows that AIDS continues to be a Stigmatized Disease. Retrieved Oct. 18, 1998, from the World Wide Web: http://psychology.ucdavis.edu/rainbow/html/geneva98.html

NASW (National Association of Social Workers (1996). HIV/AIDS. In (Ed.), Social Work Speaks - NASW Policy Statements (4th ed., Rev., pp. 159-163). Washington, DC: NASW Press.

WHO (World Health Organization) (Dec. 1998). Global HIV/AIDS & STD Surveillance. Retrieved Oct. 25, 1998, from the World Wide Web: http://www.who.int/emc-hiv/global_report/slides

University of California at Davis - Psychology Dept. (1998). Gregory M. Herek, Ph.D. - Biographical Sketch. Retrieved Oct. 25, 1998, from the World Wide Web: http://psychology.ucdavis.edu/rainbow/html/bio.html

The Studies Attached Are For Your Review

All These Reports Indicate That HIV Reporting
Is Better Accomplished
By Using Systems With Unique Identifier Codes
Rather Than Reporting Cases By Name

American Civil Liberties Union Report

October - 1997
Recommending HIV Reporting Be Done By
Unique Indentifying Codes Rather than By Name

National Association of People With AIDS Position on HIV Surveillance

Adopted October 3, 1997
Recommending HIV Reporting by UI Codes

Report Showing the Failure of HIV Name Reporting In New Jersey

Published February 28, 1998
Illustrated that Names Reporting Requirements
Prevented People from Being Tested for HIV

Report Showing the Success of Reporting by UI Codes In Maryland

Published April, 1998
Illustrated the Use of Non-Name Based Identifier
Was Successful in Tracking HIV Prevalence and in Not Discouraging
People from Being Tested

Thank you,
Don Carrel

"HIV Surveillance and Name Reporting"

A Public Health Case for Protecting Civil Liberties
An American Civil Liberties Union Report
October 1997

Reprinted Below is the Conclusion of this Report
Completed in 1997

The entire report can be retrieved from the World Wide Web at:
www.aclu.org/issues/aids/namereport.html

In this 1997 Report, the ACLU Concluded:

- **"The best evidence we have suggests that those who most need HIV testing are afraid of name reporting because they fear discrimination."**
- **"Moreover, we know those fears are not groundless."**
- **"Unless we truly provide people with HIV the protection from discrimination we have been promising them ... we cannot honestly use the availability of new treatment to get people to overcome their fears of discrimination unless we are ready to make new treatment available."**
- **"Since we have done neither ... under these circumstances, name reporting is not appropriate."**

V. CONCLUSION

There may come a time when HIV is so unremarkable a part of our social landscape, and care for it so routinely available to those who need it, that no one will reasonably fear being identified as a person with HIV. But we are nowhere close to that time yet. On the contrary, the best evidence we have suggests that those who most need HIV testing are afraid of name reporting because they fear discrimination. Moreover, we know those fears are not groundless.

We cannot honestly allay these fears unless we truly provide people with HIV the protection from discrimination we have been promising them. We cannot honestly use the availability of new treatment to get people to overcome their fears of discrimination unless we are ready to make treatment available. Since we have done neither, we cannot honestly tell people they should overcome their fears of testing. Under these circumstances, name reporting is not appropriate.

American Civil Liberties Union

October 03 1997

NAPWA Position Statement on HIV Surveillance

(Adopted October 3, 1997)

Policy Position Paper on Monitoring of the HIV Epidemic

The following criteria define NAPWA's position on the responsible and ethical approach to monitoring the HIV/AIDS epidemic in the United States. Collectively, these fourteen criteria define a comprehensive approach to both our nation's surveillance system and our nation's HIV counseling and testing system, as well as federal public policy and civil rights concerns.

1. Under no circumstance does NAPWA support HIV named reporting, the CDC's promotion of a national standard in support of HIV named reporting or the creation of a federal name-based registry of people living with HIV/AIDS. The CDC should in no way encourage or require states to do HIV named reporting.

2. NAPWA guardedly supports the expansion of our national HIV/AIDS surveillance system to include HIV infection case reporting; however, only using unique or coded identifiers that insure privacy and confidentiality of the individual.

3. The CDC must aggressively promote, expand and improve anonymous HIV testing in the United States. The availability of readily accessible anonymous testing is a necessary condition/prerequisite for any maintenance and/or expansion of HIV surveillance in the United States. CDC must mandate readily accessible anonymous testing in all HIV Prevention Cooperative Agreement jurisdictions as a condition of establishing HIV surveillance tools nationally.

4. CDC-funded research has shown that certain individuals and/or communities will only use anonymous testing sites. Therefore, access to primary care (after testing positive) is predicated upon the availability of anonymous testing.

5. CDC's HIV/AIDS surveillance's primary goal is to collect useful data in a timely fashion to provide an accurate estimate of the prevalence of HIV/AIDS in the United States. Accordingly, HIV/AIDS surveillance has to provide reliable data. As such, while it is a goal of anonymous and confidential counseling and testing to link individuals into services, this is not necessarily either a goal or an outcome of surveillance.

6. The applied uses of reliable, accurate and timely surveillance data include informing: resource allocation; health planning; and evaluation of both programmatic as well as system-wide activities (i.e. access to care, survival/death rates, seroincidence rates, etc.).

7. As a guiding principle, unless a name is uniquely essential for the protection and

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promotion of an individual's health and well-being or a community's health and well-being, the name of the person whose information is being reported to the state or local health department should not be taken.

8. Surveillance is an adaptive science. As such, surveillance systems should be constantly re-evaluated to determine if the goal of applying surveillance data to meaningful education, programs, planning and resource allocation is happening. If not, these systems should be discontinued.

9. Surveillance systems consist of several different types of activities in addition to case counting (number of individuals living or deceased who have said disease): sentinel studies; incidence and prevalence studies (density of disease and breadth of disease); and even behavioral (risk-taking) surveillance. The more varied the surveillance system, the more relevant the data sets that result.

10. Decisions regarding what type of HIV/AIDS surveillance to implement in a given jurisdiction are best made by each jurisdiction based on resources, community acceptance, confidentiality/privacy protections, the severity of the epidemic, and other local considerations.

11. Data from HIV case reporting must be appropriately disseminated to the community planning bodies within jurisdictions for use in both prevention and care planning.

12. Categorical funding for HIV/AIDS surveillance must be maintained and augmented. However, resources for HIV/AIDS surveillance must not come at the expense of resources for HIV-related research, care and prevention (both primary and secondary) programs.

13. National HIV/AIDS public health policy should reinforce that the data collected under this system must remain decoupled from partner notification and contact tracing processes. These processes' relationship to surveillance must be made only as a component of and only with the explicit concurrence from the jurisdiction's HIV Prevention Community Planning group.

14. Federal law must establish an individual's enforceable right to privacy with respect to individually identifiable health information, and must protect each person from discrimination based on real or perceived health and/or genetic status. Such laws must include strong and enforceable repercussions for those individuals and systems that breach an individual's confidentiality and/or privacy. --

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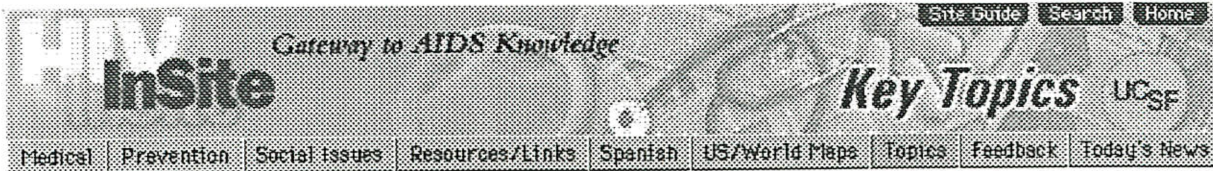

March 19, 1998

Name Based HIV Case Reporting Fails in New Jersey -- Why Institute It in New York?

by Anna Forbes MSS AIDS and Women's Health Policy Consultant phone: (610) 649-8113, e-mail: aforbes@critpath.org. Re-printed from "New York AIDS Issues Update -- 2/20/98", published by Housing Works, Inc.

The New York AIDS Advisory Council is now deciding whether and how HIV case reporting should be implemented it in New York State. So far, 31 other states have established some form of name-based HIV case registry. These states, however, are home to only about 25% of all Americans with HIV.(1) New York is among the "high incidence" states and territories that have, so far, refused to do HIV reporting. The others are California, Georgia, Illinois, Maryland, New York, Pennsylvania, Puerto Rico and Texas.

In January, 1992, New Jersey became the first high incidence state to adopt name-based HIV reporting. Given its proximity, it is worth checking to see how effectively the policy captures the real number of HIV positive residents in the state.

The AIDS Action Council reports that, when New Jersey instituted name-based HIV reporting, it simultaneously received "a CDC grant of $450,000 for a computer surveillance program.(2) This windfall was from the $5 million that the CDC added to its Surveillance budget in 1991 to "help states adopt name-based HIV reporting. "(3)

The CDC now estimates that the ratio of people with HIV in US to people living with AIDS is between 3:1 and 4:1.4 As of last September, an estimated 13,441 New Jerseans were living with AIDS (35,681 cases reported minus 22,240 known dead). But only 12,955 New Jerseans had been reported with HIV infection (the net number reported after eliminating the out-of-state reports, those that are missing data or under investigation and those that have been moved from the HIV to the AIDS registry)

Instead of having three to four times as many people with HIV as with AIDS (as expected according to the CDC ratio), New Jersey has fewer residents living with HIV (12,955) than with AIDS (13,441). What happened to the 27,000 to 41,000 New Jerseans who should be reported as having HIV if the CDC ratio is correct? Why aren't they appearing in the state's HIV case reporting numbers? Only 1,237 of the HIV reports filed were "anonymous reports", records of people testing positive at one of the state's six remaining anonymous test sites. So this deficit in HIV reports can't be attributed to people accessing anonymous testing.

Having eliminated that, here are four other possible explanations:

1) New Jersey is doing such a good job of preventing HIV transmission that only a very

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small number of new infections are occurring. Because only a tiny number of people get infected annually, the number of people living with HIV isn't increasing any faster that the number of people living with AIDS in the state.

2) people with HIV aren't getting tested and, therefore, aren't showing up in the HIV registry.

3) New Jerseans are getting HIV tests but not in New Jersey. Anecdotal reports of New Jerseans traveling to nearby states that do not have name reporting requirements (usually Pennsylvania or New York) for their HIV tests are common.

4) people who can afford it are purchasing and using home test kits for HIV.

The state surveillance report shows that, while 26% of the New Jersey men diagnosed with AIDS in 1996-97 are Caucasian, only 21% of men reported as HIV positive in New Jersey since 1992 are white. African American men, on the other hand, make up 53% of the men diagnosed with AIDS but 56% of men reported with HIV in those two time periods. The percentages by race of women recently diagnosed with AIDS and those reported as HIV positive more nearly match.

We can also see that, while men who have sex with men made up 24% of the New Jersey men diagnosed with AIDS last year, they accounted for only 20% of men reported as HIV positive since 1992. Injection drug users, on the other hand, made up 36% of the men diagnosed with AIDS last year but 42% of all men reported with HIV since 1992.

These gaps in the numbers show that the names of white men and gay/bisexual men are less likely to show up on New Jersey's HIV registry than are the names of men of color. If one sees this a being an economic effect (i.e. that affluent people are better able to evade state HIV reporting requirements than those with fewer resources), it is not surprising that it is more evident among men than women. Women with HIV/AIDS tend, overall, to have low incomes regardless of their race or risk factor.

These reporting differences may illustrate the extent to which possibilities #3 and #4 impact on the number of New Jerseans reported with HIV. But they aren't large enough to answer the real question of why New Jersey's HIV registry contains 30,000 - 40,000 fewer names than expected given the number of New Jerseans living with AIDS. To explain that huge discrepancy, we have to look at possibilities #1 or #2.

If you believe that #1 is the primary explanation, then you will laud New Jersey for its exemplary HIV prevention efforts. But if you believe that #2 is more likely to be the cause, then New Jersey is facing an enormous public health challenge. No correlation has been shown between state adoption of name-based HIV reporting and enhancement of the state's ability to assure medical care to its residents. But studies have consistently shown a correlation between adoption of name-based reporting and public unwillingness to be tested for HIV.

In a recent CDC-funded survey of high risk individuals, 19% -- almost one in five -- identified name reporting as a reason not to get an HIV test. The ACLU's 1997 report on this subject summarizes nine other studies that document a link between name-based reporting and testing avoidance.(5) In one California study, 60% of the individuals surveyed

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indicated that they would avoid HIV testing altogether if getting tested meant risking name-reporting.(6) The ACLU report also points out that, "the deterrent effect of name reporting is most pronounced in the very populations with the greatest need for preventive intervention: gay and bisexual men, people of color, intravenous drug users, and sex workers."(7)

New Jersey's experience is instructive. Unless there are specific reasons to believe that this failure won't be replicated in New York State, it makes no sense for the AIDS Advisory Council's HIV Surveillance Working Group to recommend name-based reporting as a way of getting an accurate picture of how many New Yorkers are HIV positive. New Jersey's experience shows that it simply doesn't work.

End Notes

1. L.O. Gostin, J.W. Ward, and A.C. Baker, National HIV Case Reporting for the United States -- A Defining Moment in the History of the Epidemic," The New England Journal of Medicine 337, no. 16 (October 16 1997): 1162-67.

2. AIDS Action Foundation, "Should HIV Resuts Be Reportable?: A Discussion of Key Policy Questions, " White paper published by the AIDS Action Foundation, Washington DC, March 1993.

3. J. Prosid, Deputy Branch Chief, Surveillance Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention (Oral presentation at "Consultation on the Future of HIV/AIDS Surveillance", Atlanta, GA, 22 May, 1997).

4. P.L. Fleming, Chief, Reporting and Analysis Section, Surveillance Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention (oral presentation at "New York State AIDS Advisory Council HIV Surveillance Work Group Meeting", New York, NY, 17 December, 1997).

5. American Civil Liberties Union, "HIV Surveillance and Name Reporting: A PublicHealth Case for Protecting Civil Liberties", 3-7.

6. Kegeles SM; Catania JA; Coates TJ; Pollack LM; Lo B. Many People Who Seek Anonymous HIV-Antibody Testing Would Avoid It Under Other Circumstances, AIDS, 1990 Jun, 4:6, 585-8.

7. American Civil Liberties Union, "HIV Surveillance and Name Reporting: A PublicHealth Case for Protecting Civil Liberties", 4.

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October 14, 1997

HIV Test-Seeking Before and After the Restriction of Anonymous Testing in North Carolina

Hertz-Picciotto I; Lee LW; Hoyo C. Am J Public Health, 1996 Oct, 86:10: 1446-50

Abstract

OBJECTIVES: This study assessed the impact on HIV test-seeking of North Carolina's restriction of anonymous testing to 18 of its 100 counties as of September 1, 1991.

METHODS: Trends from 4 months prerestriction to the 16-month restriction period in counties retaining vs counties eliminating anonymous testing were compared.

RESULTS: HIV testing increased throughout the state, but more rapidly where anonymous testing was retained than elsewhere: 64% vs 44%. These differences held for all sociodemographic subgroups and were most pronounced among adolescents and African Americans and other non-Whites.

CONCLUSIONS: The data are consistent with a detrimental effect of elimination of anonymous testing, although confounding from differences in AIDS awareness or in repeat tests is possible.

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April 01, 1998

HIV Surveillance by Non-Name Based Identifier, the Maryland Experience

By Liza Solomon, Director of the Maryland AIDS Administration. Reprinted from NASTAD HIV Prevention Community Planning Bulletin, April 1998.

In order to enhance our understanding of the full spectrum of HIV disease and to better understand the epidemiology of those newly infected with HIV, Maryland implemented a system of HIV surveillance. Beginning in 1994 Maryland began HIV reporting using non-name based unique identifier (UI) codes. This report describes the Maryland system, how it works, and presents some initial findings from the Maryland evaluation.

Why non-named-based HIV surveillance?

Maryland's UI system was implemented after attempts to institute HIV name reporting were defeated in the Maryland legislature in 1992 and 1994. An important consideration in the defeat of a name-based surveillance system was concern that such a system would discourage individuals from seeking HIV testing and thus delay treatment. The decision to move forward with a UI-based HIV surveillance system was strongly supported by the HIV-affected community in Maryland.

Description of the Program

The Maryland HIV surveillance program requires that positive HIV tests and CD 4 counts of 200 or less are reported by laboratories using a unique identifier (UI). Exemptions to the UI reporting system include blood, semen or tissue donors, individuals who do not reside in Maryland, DHMH designated anonymous test sites, and some limited research activities.

The UI is a 12 digit number consisting of the last four digits of the social security number (SSN), the individual's date of birth, a digit representing the individual's race/ethnicity and a digit for the individual's gender. The provider who orders a HIV test or CD4 test creates the UI number which is sent with the laboratory requisition. The laboratory sends the UI report form for positive HIV tests and CD4 counts less than 200 to the state AIDS Administration office or to the local health department, which then forwards the report to the AIDS Administration. The AIDS Administration matches each UI received against the State AIDS Registry, (UIs were created for all records in the AIDS registry) thus creating a registry of HIV infection that is not yet reportable as AIDS. Surveillance staff call physicians as necessary to verify the UI number, check for incomplete information, and obtain information on clinical status and risk categories. Patient names are not given to the surveillance staff unless the clinician indicates that the patient has been diagnosed with an AIDS defining condition. Surveillance staff may then assist the clinician in filling out an AIDS case report.

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Implementation of the UI system

In order to get an unduplicated count of the number of individuals with HIV infection, and to be able to differentiate between newly diagnosed HIV cases from previously reported AIDS cases, it is important to have the UI code filled in accurately and completely. An evaluation of the completeness of UI elements reveals that there has been significant improvement in the completeness of UI elements over time, as providers have become more used to the UI system. While only 61 percent of the UIs were complete in the first six months of the program, 77 percent of UIs reported in the last six months of 1996 were complete. In an assessment of our ability to improve on the completeness of UI numbers, additional training was provided to staff at Counseling and Testing Sites; after the initial training period, completeness of UI numbers increased to 97 percent. This suggests that continued provider education and assistance would improve on the overall completeness of UIs.

Ongoing evaluation of the UI system - does it work?

As implementation of the UI system continues, several evaluation activities are underway. In addition to the ongoing assessment of the completeness of the UI number, the AIDS Administration has conducted an evaluation of the "uniqueness" of the UI. This analysis included two approaches, an examination of whether UIs could effectively differentiate separate individuals, and an assessment of the completeness of reporting.

To test the uniqueness of the UI we examined the records from Maryland residents in the AIDS registry in which we were able to create a full UI number. We then examined how often identical UI's would be found in a registry which should contain no duplicates. Of the 15,672 records in the AIDS registry, use of the full UI was able to correctly differentiate individuals greater than 99% of the time.

To test whether this 99% uniqueness would hold true in the field, the AIDS Administration examined all identical UIs in one jurisdiction. In a comparison of records from clients who had the same UI but had made several visits we were able to demonstrate that individuals were correctly given the same UI when they received additional HIV positive test results or additional CD4 counts. Although this analysis of uniqueness will be performed in other areas of the state to confirm this result, this initial examination suggests that the UI numbers do work to designate unique individuals.

An analysis of the completeness of reporting is currently underway. However, preliminary data demonstrates that completeness of HIV reporting in Maryland is comparable to that seen in names reporting states. According to the Centers for Disease Control and Prevention, among states that have HIV name based reporting, the ratio of new HIV to new AIDS cases varies from 0.6 (Arizona) to 1.6 (Nebraska) with a mean of 0.9. The ratio of HIV to AIDS cases in Maryland is 0.9, suggesting that the data obtained from Maryland's reporting system is comparable to that seen in name based states.

What we learned from our HIV reporting system - HIV AIDS differences

In order to appropriately plan prevention services and allocate treatment resources to areas of greatest need, both HIV and AIDS cases must be examined. A comparison of age, race and gender characteristics of those diagnosed with HIV with AIDS demonstrated significant differences in age and gender distribution. In 1996, 29 percent of new AIDS cases in

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Maryland were found among women, however, 41 percent of HIV cases in that year were seen in women. Differences in age distribution of those with HIV as compared to those with AIDS were also seen. Among cases of AIDS reported in 1996, 13 percent were among individuals age 20 to 29; however, among individuals with HIV only, 21 percent were within this age group. Also of interest is the finding that the number of individuals above 50 with AIDS is higher than those seen among individuals with HIV. An examination of race differences did not show any significant change in patterns among those with HIV infection versus AIDS, 82 percent of those with AIDS are minorities as compared to 82 percent of individuals diagnosed with HIV. Data from our HIV reporting system will be used to guide prevention and services resource allocations.

Conclusion

Maryland's UI system has provided epidemiologic data which will be of increasing importance to our states, ability to understand the changes in the HIV epidemic. The creation and maintenance of the Maryland HIV reporting system has been implemented with minimal cost and without additional federal or state support. **We believe that states considering implementing an HIV reporting system may want to consider models such as Maryland's to help provide needed epidemiologic data while protecting the confidentiality of people with HIV.**

Testimony presented to

House Committee on Health and Human Services

February 3, 1999

by

Gianfranco Pezzino, MD, MPH

State Epidemiologist

Kansas Department of Health and Environment

House Bill_HB 2074

Surveillance for HIV infection in Kansas is currently limited to confidential reporting of AIDS cases. These reports are sent by physicians to the AIDS program in the Kansas Department of Health and Environment. Reports are analyzed by program staff to describe trends in HIV infection and changing patterns of HIV transmission. This information is also used to guide allocation of funds both at the federal and at the state level. Reports of positive HIV tests without personal identifiers are also received by the KDHE but not used for surveillance purposes because of the limited information contained in these reports.

With the advent of more effective therapy that slows the progression of HIV infection into AIDS disease, surveillance systems including only AIDS reports (such the one in Kansas) are no longer able to reflect current trends in HIV transmission and to represent the extent of the

need for prevention and care services. AIDS cases are declining nationwide as well as in Kansas, primarily as a result not of lower rates of new infections but of better treatment of infected individuals identified before they develop AIDS disease. Therefore, since new AIDS cases may be the result of infections acquired years or even decades ago, they no longer represent current transmission trends.

The main objectives of a name-based, confidential HIV reporting system are the following:

- To describe current patterns of HIV infection and transmission. This information is essential to make decisions on how to target prevention programs and to evaluate the impact of these programs.
- To assure that HIV-infected individuals are referred for proper case management, including counseling and anti-HIV therapy.
- To assure confidential partner notification of sexual partners of HIV-infected individuals, following a well-established and successful model used for other sexually-transmitted diseases (STD's).

✓ It should be noted that to achieve these goals the case reports need to include the names of the infected individual. In a few states alternative systems have been tried based on unique patient identifiers other than names. These systems have proven to be very expensive and not effective and in some cases those states have decided to discontinue them and adopt confidential name-based reporting instead. As of October 1, 1998, 32 states had implemented HIV confidential reporting systems. The CDC strongly encourages states to adopt confidential name reporting, and future federal funding to states for HIV prevention programs may be based on the existence and quality of such a system.

One of the major barriers to the implementation of confidential HIV reporting has been a concern about possible breaches in the confidentiality of the records and possible misuses of these records for purposes outside the goals of the surveillance system. To address these concerns one needs to understand how disease reports in general, and AIDS reports in particular, are handled within KDHE. Each report is transmitted confidentially to the appropriate program (for example, a report of syphilis will go the STD program), where trained program staff analyze it and file it or enter the information into a computer. Both filing cabinets and computers have very strict confidentiality requirements and only authorized staff (typically, one or two people in each program) have access to the full reports. The programs has a written confidentiality policy and each employee in the program has signed a confidentiality agreement.

Specific statutes restrict the use and release of information included in disease reports to very narrow and specific cases, and HB 2074 includes similar provisions. In essence, these records are not even subject to court subpoena except in the case of a child abuse trial (in which case the report can be disclosed behind closed doors). The public health system, both in Kansas and elsewhere, has an excellent track record of protecting confidentiality, and this sense of protection is part of the public health culture. Under no circumstances would confidential information be shared with health insurance companies, employers, or anybody else.

For individuals concerned about disclosing their names if they test positive to an HIV test, HB 2074 includes the possibility of using anonymous testing sites as an alternative way to receive counseling and testing for HIV.

In summary, this bill represents an important step to develop an adequate surveillance system for HIV and AIDS, to prevent HIV transmission, and to assure that infected individuals receive appropriate medical care.

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Testimony of the American Civil Liberties Union of Kansas and Western Missouri in Opposition to HB 2074 Before the Senate Public Health and Welfare Committee, Honorable Sandy Praeger, Chair
By Eddie M. Lorenzo, Legal Director
March 17, 1999

I. Introduction

Good morning. My name is Eddie Lorenzo. I am the Legal Director for the American Civil Liberties Union of Kansas and Western Missouri. The ACLU is a non-profit advocacy organization devoted to the defense and promotion of the Bill of Rights. Our office in Kansas City serves all of Kansas and the western half of Missouri. We are a membership organization with over 2,500 members in this region. In Kansas, we have chapters in Wichita and at the University of Kansas.

Since the start of the HIV/AIDS crisis, the American Civil Liberties Union has worked to protect the civil liberties of persons with HIV and AIDS. Specifically, the ACLU has fought discrimination against persons with HIV and AIDS in workplaces and communities, has protected persons with HIV and AIDS against invasions of their most basic privacy, and has worked to ensure equal access to adequate health care.

The ACLU stands in opposition to HB 2074, which would require physicians and laboratory directors to report the names and addresses of persons testing positive for HIV to the Secretary of Health and Environment. There are three reasons the ACLU opposes this bill. First, evidence shows that name reporting discourages people from being tested for HIV. Second, no reliable safeguards exist, legal or otherwise, which would ensure the privacy of those who test positive for HIV, and which would protect them from discrimination. And finally, alternative methods for HIV tracking exist which do not require name reporting.

II. Name Reporting Discourages People From Being Tested For HIV

While the goal of increased tracking of HIV infection is to bring those with HIV into the public health system and to obtain more accurate data on HIV, name reporting would likely have the opposite effect.

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Evidence strongly suggests that name reporting is a counterproductive public health measure that would cause individuals to avoid HIV testing. Numerous studies indicate that individuals avoid HIV testing that is not anonymous because they do not have faith that test results will remain confidential and fear the stigma and discrimination that is often associated with HIV and AIDS. One study found that over 60% of individuals tested would not have tested if their names were reported to public health officials.[1] By contrast, anonymous testing encourages individuals to seek testing in the belief that they will be able to control the dissemination of information about their HIV status. People are more likely to be voluntarily tested for HIV if the testing is anonymous.[2]

The deterrent effect of name reporting is most pronounced in the very populations with the greatest need for preventive intervention: gay and bisexual men, people of color, intravenous drug users, and sex workers.

Research indicates that gay men are more likely to be aware of name reporting requirements and, as a result, are more likely to avoid testing altogether.[3] In South Carolina, after anonymous testing was eliminated, the number of men who have sex with men who were tested for HIV dropped by 51%.[4]

Name reporting is also likely to deter HIV testing by African-Americans and Latinos.[5] Researchers from the New York City Department of Health found that 22% of African-American and Hispanic participants would not be tested for HIV if their names were reported to public health officials.[6] One clinician commented that mandatory name reporting "will be the final blow" alienating minority women from clinicians and the health care system, causing them to go "underground fast."[7]

Other groups are also deterred from HIV testing by name reporting. Intravenous drug users and sex workers, many of whose primary contact with government has been through the criminal justice system, are more likely to test anonymously. One study found a 56% increase in HIV testing among female sex workers and a 17% increase among intravenous drug users when anonymous testing was available.[8] Women, in general, are often wary of mandatory name reporting schemes. One study found that mandatory name reporting led to a 31% decline in the number of women agreeing to an HIV test as they sought Ob/Gyn care.[9]

In sum, evidence indicates that rather than helping to control the spread of HIV and AIDS and encouraging earlier medical intervention, name reporting is likely to lead to decreased testing by those who most need it. That means that far from advancing the goal of gathering more accurate information and earlier medical intervention -- name reporting is likely to defeat that goal.

III. No Reliable Safeguards Exist That Would Protect People From Discrimination And Ensure Privacy

Many individuals fear taking an HIV test that is not anonymous. At the heart of the fear is concern about discrimination on the basis of HIV status and fear of their loss of privacy.

Laws cannot prevent family and friends from abandoning a loved one because she has HIV or because he is gay. Recent legal developments indicate that persons with HIV still have reason to worry about even those types of discrimination that the law is designed to address. Although it is assumed that the Americans with Disabilities Act (ADA) provided broad legal protections from discrimination against anyone with HIV, some federal courts indicate this is not the case. A federal appeals court has ruled that the ADA does not protect people with HIV who have not yet developed serious health problems, even if they have suffered from discrimination.[10] Another federal appeals court has held that the ADA does not protect many people with either HIV or AIDS from discrimination in insurance.[11] Thus, the anti-discrimination protections supposedly provided by the ADA may be becoming illusory for people with HIV.

It is unlikely that the fears of individuals at high risk for HIV can be overcome by promises that name reporting will be accompanied by privacy protections. Agencies cannot control how authorized personnel use the data to which they have access, creating a risk of both inadvertent and intentional confidentiality breaches.[12] Carelessness and simple human error can have serious consequences. In Florida, a computer disk containing the names of 4000 people with AIDS was discovered in the parking lot of a bar. Apparently it belonged to an AIDS surveillance case worker who misplaced it.[13] In New York, a log containing the names of 500 people who were tested for HIV "vanished" from a clinic.[14] Almost a week later, authorities still did not know if the log was stolen, thrown out, misplaced or destroyed.

Moreover, statutory assurances of confidentiality cannot prevent later evisceration of privacy guarantees. Just as a legislature may enact confidentiality provisions, so too may it later create exceptions or revoke protections.

Even if legal remedies, or criminal penalties, do exist for a violation of confidentiality, they would be rendered moot in practice because lawsuits and criminal complaints are public documents. A person who has suffered significant and actionable discrimination on the basis of a breach of the state's responsibility for confidentiality may choose not to file a lawsuit, or be reluctant to testify in a criminal proceeding, for fear of publicizing his or her condition even further.

In sum, the fears that drive people away from HIV testing with name reporting are real fears. To eliminate them, we need more than education; we need solid anti-discrimination protection and real privacy protections. Name reporting is not appropriate until we make progress toward these two goals.

IV. Alternative Methods For HIV Tracking Are Available

The desire for more comprehensive HIV tracking can be accommodated without name reporting. For example, HIV surveillance can be implemented through the use of a system of unique identifiers.

Unique identifiers are numeric and alpha-numeric codes that are used to identify a particular individual. We use these every day in the form of social security numbers, driver's license numbers, and account numbers. In the context of HIV testing, the concept is to create a code that identifies only one person and to associate the HIV test result with that unique identifier, rather than with the name of the individual. The code may be reported to public health authorities, providing accurate data regarding HIV infection rates along with various demographic indicators. But because the code cannot be traced back to the person tested, the anonymity of the testee is preserved.

There are sound reasons to pursue this option if expanded HIV surveillance is desired. First, by preserving the anonymity of the testee, a unique identifier system encourages individuals to be tested and enlists the support of community organizations that are opposed to name reporting. Second, it is at least possible that unique identifier systems may ultimately provide better data than name reporting confidential testing.[15] In a unique identifier system, an individual will most likely use the same code for each test (e.g. birth date and the last four digits of social security number). With one unique identifier composed of intimate information (so the individual remembers it), a repeat tester can be identified as such and not double counted.

Two states, Maryland and Texas, presently use unique identifier systems to track HIV cases. The experiences of both states should be analyzed to determine the benefits and drawbacks of unique identifiers, and to identify what work must be done to make them effective tools for HIV surveillance.

It appears that developing effective unique identifier systems will require the investment of significant time and resources. But given the evidence that name reporting will discourage testing, particularly among those who most need it for themselves and for accurate surveillance, it remains the most sensible option today.

V. Conclusion

There may come a time when HIV is so unremarkable a part of our social landscape, and care for it so routinely available to those who need it, that no one will reasonably fear being identified as a person with HIV. But we are nowhere close to that time yet. On the contrary, the best evidence we have suggests that those who most need HIV testing are afraid of name reporting because they fear discrimination, and they fear the loss of their privacy. Moreover, we know those fears are not groundless. Until we can fully respond to those fears, name reporting is not appropriate.

For these reasons, the ACLU opposes HB 2074 and respectfully requests that alternatives to name reporting be examined.

Thank you.

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[1] Susan M. Kegeles et al., Many People Who Seek Anonymous HIV-Antibody Testing Would Avoid it Under Other Circumstances, 4 AIDS 585, 586 (1990).

[2] Kathleen Irwin, et al., The Acceptability of Voluntary HIV Antibody Testing In the United States: A Decade of Lessons Learned, AIDS, vol. 10, no. 14, 1707, 1711 (1996); Geoffrey Reed, et al., The Impact of Mandatory Name Reporting on HIV Testing and Treatment, Poster Presentation for the XI International Conference on AIDS (July 1996); Douglas Hirano et al., Anonymous HIV Testing: The Impact of Availability on Demand in Arizona, 84 AM. J. PUB. HEALTH 2008, 2010 (1994).

[3] HIRANO, supra note 2, at 2009; KEGELES, supra note 1.

[4] WD Johnson et al., The Impact of Mandatory Reporting on HIV Seropositive Persons in South Carolina (1988) (Presented at the Fourth International Conference on AIDS, Stockholm, Sweden).

[5] While people of color are discussed separately from gay and bisexual men in this testimony because of the high rates of HIV infection in many communities of color, it is worth noting that the two groups are not mutually exclusive - i.e. many gay and bisexual men of color are infected with HIV.

[6] E. Fordyce et al., Mandatory Reporting of Human Immunodeficiency Virus Testing Would Deter Blacks and Hispanics from Being Tested, 262 JAMA 349 (1989).

[7] Letter from B. Joyce Simpson, RN, MPH, to Robert M. Greenstein, Director of Division of Human Genetics, University of Connecticut Health Center (November 30, 1992)(on file with the ACLU AIDS/HIV Project).

[8] Laura Fehrs et al., Trial of Anonymous Versus Confidential Human Immunodeficiency Virus Testing, 2 LANCET 391 (1988).

[9] B. Lo et al., AIDS Screening: Who is Willing to be Tested (1988)(Presented at the Fourth International Conference on AIDS, Stockholm, Sweden).

[10] *Runnebaum v. Nationsbank of Maryland*, 95 F.3d 1285 (4th Cir. 1997) (en banc).

[11] *Parker v. Metropolitan Life Insurance Company* __F.3d__, (6th Cir. Aug. 1, 1997) (en banc).

[12] Robert Trigaux, Leak sparks security fears, St. Petersburg Times, September 20, 1996, at 1A. See also Lawrence O. Gostin, Health Information Privacy, 80 Cornell L. Rev 451, 493 (1995)("It is the proliferation of...legitimate users of information that pose the greatest risk to informational privacy").

[13] Sue Landry, AIDS list is out, St. Petersburg Times, September 20, 1996, at 1A.

[14] Log, Said to List AIDS Test-Takers, Is Lost, N.Y. Times, April 23, 1987, at A21.

[15] Anna Forbes, Mandatory Name-based HIV Reporting: Impact and Alternatives, AIDS Policy & Law, May 1996.

KANSAS MEDICAL SOCIETY

March 17, 1999

To: Senate Public Health and Welfare Committee

From: Jerry Slaughter
Executive Director

Subject: HB 2074; concerning named reporting of HIV

The Kansas Medical Society appreciates the opportunity to testify on HB 2074, which relates to reporting requirements for HIV infected patients. KMS supports this bill, which requires physicians to report the names and addresses of individuals who they know have contracted HIV to the secretary of health and environment. It appears that without this bill important federal funding for HIV and AIDS programs could be in jeopardy.

By passing HB 2074, the legislature would help to ensure that federal funding for these HIV and AIDS programs continues. It would also allow KDHE to gather more comprehensive data on the incidence and prevalence of HIV and AIDS patients in our state. While we support the bill, KMS strongly urges the legislature, and KDHE, to do all that they can to protect the confidentiality of sensitive information collected through named reporting.

The Centers for Disease Control (CDC) has developed guidelines on reporting of HIV and AIDS information. The CDC strongly encourages states to provide publicly funded anonymous testing and counseling sites throughout the state. KMS agrees with this recommendation. Studies have shown that persons are much more willing to be tested for the AIDS virus if they can be assured that the testing is done anonymously with no reporting. Maintaining access to anonymous HIV testing is critical to encouraging some to get tested, which helps in the overall public health response to AIDS. We support the House amendment in Section 6 to assure the availability of anonymous testing sites statewide.

We also support the other House amendments to the bill regarding the time period for reporting by physicians and the reference to confidentiality concerns.

Thank you very much for considering our comments. I would be happy to respond to questions.

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