Approved: February 23, 1999
Date

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES.

The meeting was called to order by Chairperson Garry Boston at 1:30 p.m. on February 4 at the Dillon House.

All members were present except: Representative David Haley, Excused

Committee staff present:
Emalene Correll, Kansas Legislative Research
Norman Furse, Revisor of Statutes
June Evans, Secretary

Conferees appearing before the committee:
Sally Finney, Executive Director, Kansas Public Health Assn.
Meg Draper, Director of Government Affairs, Kansas Medical Society
Ben Klein, former Executive Director of Connect Care, Wichita
Doug Glaze, Wichita
Gianfranco Pezzino, M.D., MPH, State Epidemiologist, Kansas Department of Health and Environment
Don Carrel, Aids Educator, Mission, Kansas
Sue Chipman, Health Education Instructor, Prairie Village
Shellie Brandon, Lenexa, Kansas
Alva Dean Cook, Jr., M.D.
R. Michael Lawler, Ph.D., CAE, Executive Director, Aids Council of greater Kansas City

Others attending: See Attached Sheet

The Chairperson called the meeting to order and stated the hearing would be continued on **HB 2074 - HIV and AIDS monitoring.**

The fiscal note was distributed yesterday and staff gave a briefing yesterday.

Sally Finney, Executive Director, Kansas Public Health Association, Inc., testified as a proponent to **HB 2074**, a bill that changes the state's current reporting system for cases of HIV infection to include patient names. The Kansas Public Health Association supports this legislation because of the benefits it is believed it would create. Specifically, named HIV case reporting would help to achieve the following: (1) Assure that infected individuals are linked to the public health system to receive information about treatment options and available resources to support care. (2) Strengthen the public health system's ability to reach out to individuals who may have been exposed to infected persons through high-risk behavior. (3) Significantly improve the state's ability to monitor the spread of HIV into various population.

One myth about the impact of implementing a name-based reporting system is that people would 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. KPHA believes that **HB 2074** means 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. (See Attachment #1)

Meg Draper, Director of Government Affairs, Kansas Medical Society, testified as a proponent for **HB**

2074. 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. By passing **HB 2074**, the legislature would help to ensure that federal funding for HIV and AIDS programs continues. It would also allow the department of health and environment to gather more comprehensive data on the incidence and prevalence of HIV and AIDS patients in our state. KMS strongly urges the legislature to do all that it can to protect the confidentiality of sensitive information collected through named reporting. (See Attachment #2)

Benjamin Klein, former Executive Director of ConnectCare (the state's largest provider of client services and prevention programs exclusively addressing HIV and AIDS), person living with AIDS, and member of the state HIV/AIDS Care Consortium, testified as a proponent for **HB 2074.** The bill as written fully addresses the Centers for Disease Control (CDC) guidelines for mandatory tracking and reporting, and insures compliance. The adherence to those CDC guidelines and implementation to use information gathered in a secure and confidential manner with the goal of providing early access to care, disease monitoring and tracking and improved prevention programs to stop the spread of HIV in Kansas is appreciated. The time is here to track HIV infection and aggressively help those infected access medication and primary care in order to remain healthy and independent taxpaying Kansans. With HIV reporting, can also hit with strong prevention efforts to those infected, their partners and those at highest risk for where the disease is moving today rather than where it was eight to ten years ago. (See Attachment #3)

Doug Glaze, Wichita, testified as a proponent to **HB 2074**, stating he has been living with HIV since 1984 and has spent most of his adult life volunteering, speaking and working on HIV and AIDS related issues. If the purpose of this bill is to inform our state officials and service providers as to how many people are living with HIV in the state of Kansas, and this bill actually discourages people from being tested for HIV, then this bill as currently written serves no practical purpose at all. If people do not take a test to see if they are infected with HIV, then the state can collect no data regarding them. It is hoped the strongest possible language be added to ensure that all Kansans who wish to receive an HIV test be able to do so anonymously. Doing so would not effect the essential provision of this bill; that is, creating the ability to track HIV infection in Kansas. An anonymous HIV test is currently available to any Kansan who wishes one and this should remain true. (See Attachment #4)

Don Carrel, Aids Educator, testified on **HB 2074**, stating he has been living with AIDS and believes he was infected in 1982, but suffered absolutely no symptoms for 13 years. In 1995 he developed pneumocystis pneumonia and was forced to closed his business and retire. Since then he has volunteered, talking to students in Johnson County. 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 simply do not believe they are at risk for HIV. HIV testing should be voluntary, confidential, and performed with informed consent. In addition, anonymous testing should be available, accessible, and free. (See Attachment #5)

Dr. Gianfranco Pezzino, MD, MPH, testified stating that 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.

The main objectives of a name-based, confidential HIV reporting system are the following: (1) 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. (2) To assure that HIV-infected individuals are referred for proper case management, including counseling and anti-HIV therapy. (3) 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). 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. (See Attachment #6)

Sue Chipman, Health Education Instructor, Shawnee Mission East High School, Mission, Kansas, testified in favor of **HB 2074**, stating their purpose was in educating young people to help them make informed choices. One fourth of all people infected with HIV are infected by the age of 19. One half of all those infected are infected by age 25. The teenage population group is one of two groups in which this disease in increasing most rapidly. The purpose of testing is to allow people to make informed choices if they find they are infected. If people are afraid to be tested, they would be unaware of their HIV status. Only education, non-threatening testing procedures and awareness of the process of this disease will make it go away. (See Attachment #7)

R. Michael Lawler, Ph.D., CAE, Executive Director, Aids Council of greater Kansas City, testified in support of **HB 2074**, stating name-based HIV reporting should only occur when: (1) The state provides strong penalties to deter state personnel and others affected by the law from misusing information about the HIV status of an individual. However, under both existing law and **HB 2074**, breaches of confidentiality are "Class C" misdemeanors. A "Class C" misdemeanor – which results in a fine of no more than $300 and/or a maximum of 15 days' incarceration – is not a strong deterrent. (2) There must be an adequate number of strategically placed anonymous testing sites so that no one avoids HIV testing due to fears about breaches of confidentiality. **HB 2074** allows the Kansas Department of Health and Environment to set policy regarding anonymous testing. KDHE officials have indicated that they will be establishing anonymous testing sites if **HB 2704** is approved. (See Attachment #8)

Shellie Brandon, Lenexa, Kansas, testified in support of **HB 2704**, stating some of the risks faced by an HIV/AIDS infected person are the social risk, and social vulnerability – just knowing someone has "taken the test" could cause specific losses to one's social or economic capital should it become known in various fields of life that one has HIV; was tested for HIV or has behaved in ways to put himself at risk for having HIV. (See Attachment #9)

Alva Dean Cook, Jr., M.D., testified that HIV has not been treated as other communicable diseases for very good or bad reasons. Many people with this condition are homosexual and many are not. (See Attachment #10)

Sherry Karen Baer, LSCSW, Executive Director, Topeka Aids Project, not either a proponent or an opponent testified the bill has far-reaching ramifications. There are four areas of the bill with particular diligence: (1) Section 2. Women and men of good will have strong opinions about the veracity of names reporting. Need to weigh the cost of the potential public good to be derived against the loss of individual rights to privacy when considering these provisions. (2) Section 3. (a) This section gives wide-ranging but ill-defined power to the Secretary of Health and Environment to adopt and enforce rules and regulations for the prevention and control of HIV infection or AIDS. There needs to be greater clarity. (3) Section 4. (B) This section allows a physician to disclose HIV status to a partner or spouse without consent of the infected person. There is grave concerns about this erosion of patients' rights. (4) Section 6. While a proviso for anonymous testing is applauded, do not believe the current language adequately addresses the issue of available, accessible, and free. (See Attachment #11)

The Chairman closed the hearing on **HB 2074.**

The Chairman appointed a Sub-Committee on **HB 2074:** Representative Phyllis Gilmore, chairperson, Representative Bob Bethell, Representative Sue Storm, Representative Judy Showalter, Representative David Haley and Representative Peggy Long. The Charge to the Sub-Committee was to report back to the full committee on or before February 18, 1999, with recommendations regarding confidentiality issues surrounding testing for HIV under **HB 2074.** Specifically, can a compromise be struck between the concerns of those tested relating to information being held in strict confidence and yet be timely and correct information delivered efficiently so this data can be used to protect the general health and well-being of the public. They may include "breach of confidentiality" penalties as well as the patients right to privacy versus the public's need to know.

Written testimony only: Liatris Studer, Wichita (Attachment #12)

The meeting adjourned at 3:15 p.m. The next meeting will be February 8, 1999

HUMAN AND HEALTH SERVICES

DATE 2-4-99

NAME	REPRESENTING
Alva Dean Cook [illegible]	
Sug Clusman	
Keith E. Cook	
Shellie Brandon	
DON CARREL	
~~Elizabeth Jesse~~	
Benjamin Klein	~~STATE~~ KANSAS CARE CONSORTIUM
Doug Glaze	people living w/ HIV & AIDS
Pat Hays	KDHE
LIATRIS STUDER	KANSAS PREVENTION CPG
Carolyn Middendorf	KSNA
Barbara Holzmark	Nat'l Council of Jewish Women Greater, KC Section
Sherry Karen Bair	Topeka AIDS Project
Kelly Anderson	Topeka AIDS Project
PAM McCULLOUGH DDS	GENERAL DENTIST
PHIL ZIVNUSKA	KDA
Jon W. Tilton	KDA
Jerry Finney	Topeka AIDS Project
Mike Lawler	AIDS Council of Greater Kansas City
Michelle Peterson	Peterson Public Affairs Group
Stacy Seldon	Hein & Weir Chtd
Meg Draper	KS Medical Society
Danielle Noe	Governor's Office

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Testimony on HB 2074
Presented by Sally Finney, Executive Director
on February 3, 1999

Thank you, Mr. Chairman and members of the committee, for allowing me to appear before you today. 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

HHS
2-4-99
Atch# 1

> the data. The resulting data set is one that, under standard epidemiologic practices, is considered 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.

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.

KMS
KANSAS MEDICAL SOCIETY

February 3, 1999

TO: House Health and Human Services Committee

FROM: Meg Draper M. Draper
Director of Government Affairs

SUBJ: HB 2074: 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.

By passing HB 2074, the legislature would help to ensure that federal funding for HIV and AIDS programs continues. It would also allow the department of health and environment to gather more comprehensive data on the incidence and prevalence of HIV and AIDS patients in our state. KMS strongly urges the legislature to do all that it 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 if we are to move ahead with an effective public health response to the AIDS epidemic. We therefore ask that Section 6 on page 5 of the bill be amended to ensure that an adequate number of anonymous test sites are maintained in addition to sites where named testing is conducted. A proposed amendment is attached to this testimony.

We would also like to bring section 2 of the bill to your attention. Under current law, physicians and laboratory directors who have information indicating that a person has contracted HIV to report that information to the secretary of health and environment within a week of receipt or interpretation of the positive test results. The new language maintains the one week requirement for physicians, yet gives laboratory directors 30 days from the date of testing to provide the report to the secretary. We question the change in law to allow lab directors this extended period of time to report this information.

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

HHS
2-4-99
Atch #2

2-8

(c) Nothing in this section shall be construed to create a duty to warn any person of possible exposure to HIV.

(d) Any physician who discloses or fails to disclose information in accordance with the provisions of this section in good faith and without malice shall have immunity from any liability, civil or criminal, that might otherwise be incurred or imposed in an action resulting from such disclosure. Any such physician shall have the same immunity with respect to participation in any judicial proceeding resulting from such disclosure.

Sec. 5. K.S.A. 65-6005 is hereby amended to read as follows: 65-6005. Any person violating, refusing or neglecting to obey any provision of K.S.A. 65-6001 through 65-6004 or of the rules and regulations adopted by the secretary for the prevention and control of *HIV infection or* AIDS shall be guilty of a class C misdemeanor.

Sec. 6. K.S.A. 65-6007 is hereby amended to read as follows: 65-6007. The secretary shall establish and maintain test sites throughout the state where ~~the anonymous~~ testing for HIV may be undertaken, including anonymous testing~~. Anonymous testing for HIV may be conducted at such sites as the secretary specifies.~~

Sec. 7. K.S.A. 65-6003, 65-6005 and 65-6007 and K.S.A. 1998 Supp. 65-6001, 65-6002 and 65-6004 are hereby repealed.

Sec. 8. This act shall take effect and be in force from and after its publication in the statute book.

House Bill #2074
HIV Names Reporting
House Committee on Health and Human Services

Statement of support from Benjamin Klein, former Executive Director of ConnectCare (the state's largest provider of client services and prevention programs exclusively addressing HIV and AIDS), person living with AIDS, and member of the state HIV/AIDS Care Consortium.

As representative of the Kansas Care Consortium, a community based, state-wide membership of HIV and AIDS service organizations, care providers and individuals living with HIV and AIDS, I wish to express support of proposed bill #2074. The bill as written fully addresses the Centers for Disease Control (CDC) guidelines for mandatory tracking and reporting, and insures compliance. We appreciate the adherence to those CDC guidelines and implementation to use information gathered in a secure and confidential manner with the goal of providing early access to care, disease monitoring and tracking and improved prevention programs to stop the spread of HIV in Kansas.

In my former role as Executive Director of ConnectCare an ongoing concern has been that we did not know the scope of HIV infection, only AIDS reported cases. Funding and prevention programs have been based on the AIDS reported numbers that reflect the profile of the disease eight to ten years after infection. While anecdotally I was aware that the face of HIV infection was rapidly changing we were unable to direct adequate prevention programs to the faster growing infected communities because those statistics were not tracked. In addition care dollars allocated on AIDS numbers have been stretched each year to cover those clients with HIV who were not figured in our share of Federal funding.

The times is here to track HIV infection and aggressively help those infected access medication and primary care in order to remain healthy and independent taxpaying Kansans. With HIV reporting we can also hit with strong prevention efforts to those infected, their partners and those at highest risk for where the disease is moving today rather than where it was eight to ten years ago. I thank you for your attention to this matter and the opportunity to work together throughout the State to solve the growing threat of HIV and AIDS.

There are a few issues that need to be addressed as we approach implementing HIV Names Reporting in Kansas.

1) We need to be able to tell those that we are encouraging to be tested and requiring that their names be reported who will have no other insurance or ability to pay, that they will have access to medical care, disease monitoring through routine laboratory tests and uninterrupted access to medications. This means State funds to help carry the cost of providing these basics. Based on current resources, 1999 Federal allocations and projections of need:

    a) The estimated cost for medications per client is $800 per month, or $9,600 per year.
    b) The cost to provide monitoring (viral loads, other labs for necessary medical monitoring) is not less than $300 per visit and needed an average of 4 times per year, or $1,200 per client.

    With implementation of the full parameters of the HIV reporting bill, including partner notification and further outreach to encourage testing, we project an additional 50 to 100 new clients needing to access medication and medical care assistance because they are without other resources, i.e. private insurance. This figures to $540,000 to $1,080,000.

HHS
2-4-99
Atch#3

Current Federal Funding will not cover the added client burden to guarantee even the minimum of access to current medications.

2) As detailed in the CDC guidelines and supported in House Bill 2074, anonymous testing sites must be a part of the design of the names identification tracking. This supports the commitment to confidentiality even to those that do not choose anonymous testing, while offering those that would not come in for testing because of names reporting a way to enter the system. Research has shown that once someone has tested positive, even through an anonymous testing site, that through appropriate counseling and distribution of information, they enter into the care system. Once in the care system accessing medications and primary care, they enter into the names tracking.

   It is important to insure that any Kansan, regardless of where they live, has access to anonymous HIV testing if we indeed believe the most important goal is to find, treat and stop HIV.

3) The public and those working directly with testing and the flow of information throughout the state need to be educated to dispel confidentiality concerns both to ensure that confidentiality is maintained and to encourage the public trust in the use of names being reported. Because this is also critical to gaining the community acceptance and use of HIV testing while encouraging them to use the confidential names reporting access, we see a need for a commitment from the state to help with the implementation of this bill.

In summary, we come to you and ask for $500,000 in funding as follows:

1) $425,000 allocated for medications and primary care, and
2) $75,000 for state-wide training, education and promotion of this testing project as well as providing information to those testing positive on accessing resources.

I close with hope for the future. I see that in Kansas we are coming together despite diverse opinions and concerns surrounding HIV, AIDS and names reporting with common goals. Those goals are to provide reasonable care while extending the productive lives of those living with HIV with compassion and sensitivity, while designing more effective prevention efforts to stop the spread of HIV in Kansas.

H.B. 2074
HIV Names Reporting
House Committee on Health & Human Services

Honorable Members of the Committee:

My name is Doug Glaze, and I am a person who has been living with HIV since 1984 - my senior year in high school. Since that time I have spent most of my adult life volunteering, speaking and working on HIV and AIDS related issues. I have served with the Topeka AIDS Project, the Kansas HIV Prevention Community Planning Group, ConnectCare, the Care Coordination Team and Equality Kansas. I have spoken to and worked with thousands of people from all over the state about HIV and AIDS.

During most of this time, I have worked on a day-to-day basis with people who are concerned enough about these issues that they have considered being tested for HIV. I have had at least as much practical experience in this area as anyone I have ever known. I do not have any special studies, reports or other scientific-sounding findings to give to you today, but I can share with you my very real experiences on this matter.

And my experience tells me that this bill will greatly discourage people from being tested for HIV.

How is this significant? If the purpose of this bill is to inform our state officials and service providers as to how many people are living with HIV in the state of Kansas, and this bill actually discourages people from being tested for HIV, **then this bill as currently written serves no practical purpose at all.** If people do not take a test to see if they are infected with HIV, then the state can collect no data regarding them.

I understand the urgent need to be able to accurately document the extent of HIV infection in Kansas. I am not here to object to this vital need. **I am here today to urge in the strongest possible terms that this committee add language to this bill that ensures that all Kansans who wish to receive an HIV test be able to do so anonymously.** Doing so would not effect the essential provision of this bill; that is, creating the ability to track HIV infection in Kansas. An anonymous HIV test is currently available to any Kansan who wishes one. *This should remain true.*

The availability of anonymous HIV testing **will not** alter the benefits a names reporting system would bring to this state. The vast majority of those already receiving an anonymous HIV test eventually go on to receive a confidential, named HIV test or enroll for services as a result of a positive test result. *Adding language to this bill to ensure that anonymous testing remains available to any Kansan who wants one will not change that.* Adding such language to this bill will only ensure that the HIV names reporting system proposed in this bill would not deter individuals from testing.

Indeed, it is possible to add language to this bill that anyone who wishes to receive HIV-related services from an agency in this state be tested by and enrolled in the HIV names reporting system. Doing so would ensure that those who need or want to be tested not be discouraged from doing so, as well as make sure that the state's information on HIV infection in Kansas is all the more accurate.

HHS
2-4-99
Atch# 4

I understand as well as anyone the terrible nature of a positive HIV test result. I know that I would never have been tested had an anonymous test not been available to me. A positive test result is one of the most personal events that can occur in an individual's life. For the state to believe that it can dictate all the circumstances of such a personal event in an individual's life without negative consequences, both for the state and the individual, flies in the face of my experience as an HIV educator and, I believe, your experiences as seasoned legislators.

I implore you to listen to these experiences, and consider the proposals in this testimony.

Thank you for your time and consideration.

Doug Glaze

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4-2

Testimony on HB 2074

Mandatory Names Reporting for HIV

Prepared by:

Don Carrel

Aids Educator

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  - Phone: 913-262-9009
    - E-mail: doncarrel@virtualhaven.com

HHS
2-4-99
Atch#5

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.**

5-2

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).

5-4

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.

5-6

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

5-7

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Recommendations to Win the War against AIDS

Prepared by Don Carrel

My years of experience in AIDS education have convinced me that a more aggressive governmental response is **desperately** needed to win the war on AIDS

I would be more than glad to provide my input and assist any legislator interested in development or improvement of programs in any of the following areas:

Education Program In Schools:

We need comprehensive HIV/AIDS education programs in all schools. During my educational programs, I always stress abstinence as the best and only form of 100% protection from all STDs, including AIDS. However the nationwide facts prove many teenagers are not choosing abstinence. The most recent figures show that 45 percent of high school students are sexually active and 65 percent of high school seniors are sexually active. Thanks primarily to HIV/AIDS education, those percentages are about five percent lower than in years past.

We cannot protect our teenagers from HIV infection unless we talk about condoms. If properly used, a condom is up to 98% effective in stopping the spread of HIV disease. Teaching teens the proper use of condoms helps them stay healthy, and does not increase the likelihood of them being sexually active. High schools with condom machines in the restrooms do not have a higher incident of sexually active students than the nationwide average.

To provide the best possible HIV/AIDS education, I would recommend funds be allocated to recruit and train HIV-positive individuals to teach HIV prevention in schools. Personal experience has proven to me, the most effective AIDS educator is the person with AIDS. My presentation to students is much more effective now than when I first started my efforts three years ago. Experience and feedback from students has helped me to improve my abilities to change their behavior. I have received thousands of letters from students. The comments below are typical of what I hear from almost all students:

"Don, you're the first person who made me understand what it feels like to have AIDS"
"Thanks for talking to my class, you should talk to the whole school"
"Thanks for teaching me the facts on how to protect myself"
"I'm a virgin and you convinced me to stay that way"
"I'm never having sex without a condom"
"My girlfriend and I have decided to go get an HIV test"
"I can't believe your medication is $3,600 a month ... I could never pay that"
"I never understood how AIDS screwed up your whole life"
"Before I have sex with anyone, I'm making them get an HIV test"

Any legislator interested in observing the effectiveness of an AIDS patients in the classroom is welcome to contact me and arrange to attend one of my upcoming sessions.

Thank you ... Don Carrel – 4839 Horton – Mission, KS 66202 – Phone: 913-262-9009
Email at doncarrel@virtualhaven.com

5-9

Massive Media Campaign and Anonymous HIV Testing Sites:

We do a better job giving people access to flu shots than we do to HIV tests. Recently, I attended an AIDS conference planned by Wyandotte County high school students. The students complained about the fact that they had to "fight with the school administrators" to convince them to allow students to be tested for HIV at school. If we wish to bring this epidemic under control things must change in regard to access to HIV tests.

Funds should be allocated for programs that set up free, anonymous HIV testing in high schools and colleges, churches, places of employment and perhaps even grocery stores. This testing should be done, not once, but on a continual basis. If this program were implemented, it would encourage many people to have an HIV test on a regular basis.

Many people do not get tested for HIV because they do not realize they are even at risk for being infected. Recently a student said to me "Don, my dad says I don't have to worry about getting AIDS unless I'm gay." According to the World Health Organization, 85 percent of all the people in the world who are infected with HIV are heterosexual. Unfortunately, many people in the United States still believe that AIDS is a "gay disease." I believe it's the government's responsibility to end this misconception immediately since it directly prevents many heterosexuals from taking precautions to protect themselves and from being tested for HIV. We must get the message out that AIDS has nothing to do with sexual orientation and everything to do with high-risk behavior.

According to the World Health Organization, of the 35 million people infected with HIV disease only ten percent know they are infected. Ninety percent of the people infected with HIV throughout the world have never had an HIV test. We need the public to understand that an infected person can easily go five to 10 years without symptoms and that everyone who is sexually active or has a history of IV drugs should be tested.

To adequately educate the public and insure those at risk for HIV infection are tested, funds for a comprehensive, and continuing media campaign are essential.

Needle Exchange Programs:

Half of new HIV infections in the United States occur as the result of sharing needles during IV drug use. Recent studies conducted by the Federal government have shown that if clean needles are provided free of charge to IV drug users, the number of HIV infections in this group is cut in half and drug use does not increase. Despite this evidence, the Federal government recently chose not to continue to fund needle exchange programs.

I am not in favor of IV drug use. But, I am in favor of stopping the spread of this disease. **Unfortunately, the lack of needle exchange programs not only results in more IV drug users being infected with HIV, it also results in the sexual partners and children of those using drugs to be infected as well. Funds need to be allocated for needle exchange programs as part of the effort to do what is needed to bring HIV under control. These programs reduce HIV infections and save lives, they do not increase drug use.**

Thank you ... Don Carrel – 4839 Horton – Mission, KS 66202 – Phone: 913-262-9009
Email at doncarrel@virtualhaven.com

5-10

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

5-11

"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

5-12

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

5-13

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. --

Home | Search | Site Guide | Medical | Prevention | Social Issues | Resources/Links | Español | US/World Map | Topics | Feedback | News

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

515

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

5-16

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

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Home | Search | Site Guide | Medical | Prevention | Social Issues | Resources/Links | Español | US/World Map | Topics | Feedback | News

5-19

HIV InSite
Gateway to AIDS Knowledge
Key Topics UCSF
Site Guide | Search | Home
Medical | Prevention | Social Issues | Resources/Links | Spanish | US/World Maps | Topics | Feedback | Today's News

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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5-18

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.

5-19

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

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.

Home | Search | Site Guide | Medical | Prevention | Social Issues | Resources/Links | Español | US/World Map | Topics | Feedback | News

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)

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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.

Testimony
On House Bill No. 2074

Mandatory Names Reporting for HIV

Prepared by:
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HHS
2-4-99
Atch#7

Good afternoon. My name is Sue Chipman. I teach health education at Shawnee Mission East High School. I have educated thousands of young adults about many different topics and issues, but none have been as important as aids education. In the 80's, we discussed aids before it really had a name. That long ago I was fearful that in years to come we would see a great increase in cases. Unfortunately that has come to pass.

Our purpose in educating young people is to help them make informed choices. After 36 years of teaching, I know that dictating what adults want students to do does not work. Any concerned adult and especially those of us who are in the classroom counsel young people to abstain from sex and drug use. The reality is that many will be abstinent, but others will not abstain. HIV disease is not a moral issue. Mandatory reporting of names for an HIV test will not help to stem the spread of the disease. Students, especially, and most adults will be threatened by the possible discriminatory actions that could result from mandatory name reporting. These individuals will not be tested. That does not mean that they will choose to be abstinent. One fourth of all people infected with HIV are infected by the age of 19. One half of all those infected are infected by age 25. The teenage population group is one of two groups in which this disease is increasing most rapidly.

The purpose of testing is to allow people to make informed choices if they find they are infected. If people are afraid to be tested, they will be unaware of their HIV status. I am reminded of the example of the ostrich with its head in the sand. Unlike the problems that disappear for the ostrich, the HIV disease will not go away. Only education, **non-threatening** testing procedures and **awareness** of the process of this disease will make it go away.

I hope that you who are in a position to help stop the spread of HIV disease by encouraging anonymous testing do not fool yourselves into thinking that passing House Bill 2074 will help. In 17 or 18 years from now, about the same amount of time we in the U.S. have been aware of HIV disease, our now four-day old granddaughter will be a teenager. I hope her generation will not have to worry about HIV disease.

Your decision about this bill will be either a step forward to help control the spread of HIV disease, or perhaps, as with the ostrich, your heads will be in the sand. I am making a plea for my granddaughter and perhaps yours by asking that you vote **NO** on House Bill 2074.

Thank you for hearing my testimony.

Sue Chipman

the
AIDS Council
of greater Kansas City

R. Michael Lawler, Ph.D., CAE
Executive Director

Legislative Alert

To: AIDS Council Board of Directors and Friends of the Council
From: Mike Lawler
RE: HB 2074 HIV REPORTING BY NAME
Date: January 29, 1999

This is to notify you of a legislative hearing on HB 2074, introduced on January 21 by Representative Melvin Neufeld. The bill will initiate name-based HIV reporting in Kansas.

Health and Human Services Committee, Room 423-S (Statehouse)
1:30 p.m., Wednesday, February 3 and Thursday, February 4

Dillon House
404 SW 9th
1:30-3:30

As you may know, Kansas and other non-HIV reporting states (Missouri is an HIV-reporting state) are moving rapidly toward name-based HIV reporting at the urging of the CDC. Name-based HIV reporting should only occur when:

- The state provides strong penalties to deter state personnel and others affected by the law from misusing information about the HIV status of an individual. *However, under both existing law and HB 2074, breaches of confidentiality are "Class C" misdemeanors. A "Class C" misdemeanor -- which results in a fine of no more that $300 and/or a maximum of 15 days' incarceration -- is not a strong deterrent.*

- There must be an adequate number of strategically placed anonymous testing sites so that no one avoids HIV testing due to fears about breaches of confidentiality. *HB 2074 allows the Kansas Department of Health and Environment to set policy regarding anonymous testing. KDHE officials have indicated that they will be establishing anonymous testing sites if HB 2074 is approved.*

Should you wish to register an opinion on HB 2074, here is a list of representatives from the metropolitan area who sit on the Health & Human Services Committee:
Phyllis Gilmore, Olathe (27th District)
Patricia Lightner, Overland Park (29th District)
David Haley, Kansas City (34th District)
Sue Storm, Overland Park (22nd District)

Telephone Numbers
800.432.3924 (Leave a message for your legislator to call you back.)
785.296.0111 (The general switchboard will connect you to any legislator's office.)

Follow-up
The AIDS Council will monitor the hearing and keep you apprised.

HHS
2-4-99
Atch #8

SHELLIE BRANDON
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Lenexa, Kansas 66215-3433
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Kansas resident in Johnson County since 1986
Kansas resident in Wichita 1984, 1985
Kansas resident in Colby 9/81 to 10/83

SOME HISTORY

Director **January 1994 to *Present***

Overland Park Church Food Pantry. (Sixth largest in an eight county area affiliated with Harvesters, the Community Food Bank)

Consultant-Trainer **June 1986 to December 1993**

KEYS Youth Services: Coordinate training of clinical staff while providing consultative services, ensuring a professional service delivery system to youth and their families. Promoted from Program Manager, where treatment was provided for multiple emotionally disturbed, chemically dependent and delinquent adolescent boys in a residential therapeutic setting.

Program Manager **August 1984 to June 1986**

Houston Achievement Place: Provided treatment in a residential therapeutic group home for several emotionally disturbed, chemically dependent and abused adolescent girls, who were primarily victims of incest. In addition, counseling services were provided to the families involved.

Program Manager **November 1983 to August 1984**

Maude Carpenter Children's Home: Attained NATFA Certification for Teaching-Parent while directing multiple chemically dependent emotionally disturbed and neglected adolescent boys.

Program Manager **December 1975 to August 1981**

Children's Home of Lubbock: Managed a satellite residential therapeutic group home for several emotionally disturbed, dependent, and neglected children in a coed, long term placement.

EDUCATION

- *Currently,* a graduate student in the School of Social Work, Kansas University
- B. A. in Human Services, Ottawa University, Ottawa, Kansas, 1989
- Fundamentals of Substance Abuse Counseling Certification
  by Johnson County Substance Abuse Services (Etta Williams)
- More than 280 Hours of Continuing Education Credits

CERTIFICATION /SPECIALIZED TRAINING

- Certified Red Cross Standard First Aid Instructor 1986 through 1996
- Gang Task Force of Johnson County, 1990
- Certified Family-Teacher - National Teaching Family Association 1982-1986
- Mandt Training and Certification 1988, '89, '90, '93
- Emergency Medical Technician: Texas Certification (1980)

COMMUNITY & VOLUNTEER SERVICE

- President, Board of Directors, Quail Valley HUD Non-Profit Housing Co-op (since 1997)
- Christian Family Services (private agency for foster care & adoptions) Annual Auction (since 1994)
- Speakers Bureau for Harvesters: The Community Food Bank (since 1995)
- Harvesters, Agency Relations Committee (1994, 1995, 1996, 1997, 1998)
- Divorce Recovery Support Group Facilitator (1991,'92)

HHS
2-4-99
Atch# 9

- Special Needs Adoption (Speaker) for Smithlawn Maternity Home (1982-'84)
- La Leche League International (1973-1976)
- La Maze Childbirth Instructor (1973-1976)

HONORS AND AWARDS

- Visions of the Heart Award (1996) Village Presbyterian Church and the Department of Human Services and Aging

Thank You for allowing me to testify, today.

To have the virus that causes AIDS, or the gene that predicts Huntington's, or a variety of other diseases that are particularly frightening, expensive, or stigmatized, is to face serious social as well as health threats.

(I) Even those merely at risk of cancer or HIV, or family members or friends of patients, may face mistreatment in social or work life arising from what the United States Supreme Court has called "society's accumulated myths and fears about disability and disease."

(2) The marginalization, sometimes even demonization, of people with diseases like tuberculosis and syphilis has been well documented by historians.

(3) Today, the notion that diagnosis or treatment of such conditions can trigger social harms is widely accepted.

(4) It is likewise accepted that social risk can deter people with, or at risk of, threatening conditions from seeking care or from complying with public health directives.

(5) In response, an impressive structure of laws and institutional policies has been erected to protect the privacy of various bits of medical information, such as The Americans with Disabilities Act (ADA)

(6) Dozens of state laws are intended to protect people with a broad range of conditions--including HIV, mental illness, and at least some genetic conditions--from discrimination in employment, public accommodations. and government programs.

(7) Mental health records enjoy special privacy protection throughout the

country.

(8) Most states have passed laws protecting the privacy-of HIV-related information, and have passed or are considering genetic privacy and discrimination statutes.

Please consider the risks faced by an HIV/AIDS infected person:

1. The social risk
    a. Danger of being socially or economically penalized should one become identified with an expensive, disfavored, or feared medical condition
    b. The perception of risk: included the experience of fear and uncertainty
2. Social vulnerability: just knowing someone has "taken the test" could cause specific losses one's social or economic capital should it become known in various fields of life that one has HIV; was tested for HIV or has behaved in ways to put himself at risk for having HIV.
    a. Threat of loss of confidentiality
    b. Threats to Employment and Health Insurance
    c. Threats to other forms of economic support (basic subsistence, housing, or various amenities). Family abandonment
    d. Fear of discrimination in housing and other services
    e. Threats of violence
    f. Threat of adverse legal action
    g. Threat to social status
3. Psychological vulnerability
4. Perceptions of Social Hostility: It has been suggested that in a generalized sense society at large is hostile to people with or at risk of HIV-- the disease, or drug use, or sexual orientation, or race--can influence testing behavior. Interviews with gay men revealed a mistrust of government and its motives, particularly a fear that over the long term HIV test information would be subject to misuse. Another study

> found that gay men were fearful of, and angry about, AIDS-phobic attitudes in the public, the press, and the government, and concluded that "fear of quarantine" is indeed a very real part of the psychiatric picture of AIDS in the United States."

5. Perceived probability of harm.

Testing has depended on the willingness of individuals to trust "the system." Free test sites are either public or privately funded. The subject must trust the testing site in its promise of confidentiality, or the state that it will maintain records confidentiality. Even home testing may be subject to the influence of social alienation: the user, for example, must accept the manufacturer's assurance that it really does not use Caller ID.

One's sense of the effectiveness of the law may clearly be affected by one's sense of the effort being expended to enforce it. One's willingness to undertake the burden of enforcing the law, and to use the law to "insure" against social risk, depends on one's sense of the pay out at the end.

The law does not make people whole. For the most part, if one is violated, after years of litigation, the system offers a more or less adequate payment, *years after the fact*, for both economic and non-economic losses. Yet it is quite possible that someone whose worry is the loss of status, family support, or job-related health coverage during a critical illness will not prospectively be comforted by the possibility of even a substantial amount of money many years down the road. A remedy may be perceived to be unavailable because of time. An extremely ill person may realize that a case is not likely to be resolved in their lifetime. Or the barrier may be the sense that obtaining relief will require more effort than the person has energy to expend.

For all the value of legislator's anti-stigma goals, we still know very little about how people at risk of HIV perceive the social risk of testing, or about how the law might help reduce those fears. What is known suggests that testing policies have not yet addressed the social fears of **teens, different sexual orientation, the poor, those residents alienated from the legal system, sex workers, drug users, and those whose social risk often comes from the law itself**. Social risk is probably not the most important concern of those deciding to test, but it may, in many cases, be playing a decisive role. Given the complexity of the decision to be tested, it seems likely that for many people fears of social risk may tip the balance of competing considerations, or may rationalize a decision to delay testing based on other fears. Researchers, policymakers, and legislators need to take a fresh look at the social factors that may reduce HIV and AIDS testing.

I am concerned that both social risk and its legal management are more complex than has been acknowledged, and require further research. There needs to be a careful analysis of the implications for HIV testing policy, public health programs, and social risk in all its psychological and social complexity.

Discrimination based on health conditions certainly happens, and so it is plausible to believe that it happens quite a bit, particularly given the availability of horror stories of discrimination and stigma. Social risk has long been thought to deter people at risk of HIV from being tested. In response, various states have passed legislation protecting the privacy of HIV-related medical information, offered anonymous testing, abstained from making HIV a reportable condition; and a web of state and federal anti-discrimination laws now protects people with HIV. **This body of law is now under legal and political attack.** Its loss would be a blow to the effort to control this epidemic. These laws, in themselves and in their application, elevate norms of tolerance and respect that may eventually foster a more favorable social climate for addressing risk.

My own research and that of others convinces me that discrimination, violence, social hostility, and legal persecutions are real problems. Thus my conclusion is not that we should forget about social risk, and give up the legal effort to protect people from mistreatment based on society's myths and fears about disease, but rather that we should begin to do a far better job addressing the problem in all its complexity.

I realize that the "state" has a particularly difficult role. I understand the concern for the "public health" and goals to provide services for those infected with HIV. The question: What is the **real goal** of this legislation? Does it take consider all of the residents of Kansas? The teenagers, the poor (consider the cost of the "anonymous home test"), the disenfranchised, those alienated from the legal system, sex workers and drug users. How many will delay testing, "cause someone might find out?" How many "would rather die" than take a chance on their identity being revealed without their permission? Does this bill, in its purest intent, promote social justice?

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9-8

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Testimony Kansas Legislative Commitee

I am Alva Dean Cook Jr.M. D. I have some knowledge of and concerns for public health issues. H.I.V. has not been treated as other communicable diseases for very good or bad reasons. Many people with this condition are homosexual and many are not. However early on it was assumed that it was a Gay or I. V. drug user disease. Drug users feared arrest but Gay men feared much worse. They feared being outed and with that loss of a job, loss of housing,or persecution and even being killed. If we in this country had legislated equal rights and equal protection under the law and prohibited discrimination for age , gender , race , national origin , religion , sexual identity or any other reason that the haters among us would use then H. I. V. would have been treated as a communicable disease. It is not too late. Legislate the Civil Rights I listed above first and mean business and then this public health measure.Our son Alva Dean Cook 111 was severely beaten by two so called men who broke into his apartment in New York City and beat him with baseball bats just because he was Gay. You believe this could not happen in Kansas or Wyoming ?

Please do the Civil Rights issue first and then this terribly important Public Health measure. If some of our citizens use the public health information to discriminate against people of different sexual identity than theirs this would be a terrible unintended consequence. Lets us as Kansans say "Hate and Discrimination are opposed and not tolerated here."

HHS
2-4-99
Atch #10

TESTIMONY REGARDING HOUSE BILL 2074

MANDATORY NAMES REPORTING FOR HIV

PREPARED BY

SHERRY KAREN BAER, LSCSW
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HHS
2-4-99
Atch#11

Testimony

Today you consider a bill with far-reaching ramifications in the areas of privacy and public health. You will hear proponents and opponents armed with much information to support their respective positions. Those positions, I believe, represent the fruits of considerable investigation and deliberation on both sides and reflect honest differences about a difficult topic.

Rather than add to the cacophony for either side, however, I would ask you to consider four areas of the bill with particular diligence:

1) Section 2. Women and men of good will have strong opinions about the veracity of names reporting. In our culture, we sometimes err in thinking that "experts" are only people with advanced degrees. I would ask you to keep in the forefront of your minds the knowledge that the most expert among us are those living with this disease and it behooves us all to listen well to their perspectives, concerns, and fears. This section contains several provisions which intrude heavily on the right to privacy. Please weigh the cost of the potential public good to be derived against the loss of individual rights to privacy when considering these provisions.

2) Section 3. (a) This section gives wide-ranging but ill-defined power to the Secretary of Health and Environment to adopt and enforce rules and regulations for the prevention and control of HIV infection or AIDS. We would ask for greater clarity about the scope this section might encompass.

3) Section 4. (b) This section allows a physician to disclose HIV status to a partner or spouse without consent of the infected person. We have grave concerns about this erosion of patients' rights and would ask that this provision be deleted.

4) Section 6. This section causes us the gravest concern. While we applaud the fact that a proviso for anonymous testing has been retained, we do not believe the current language adequately addresses the issues of available, accessible, and free. In a State the size of Kansas, four anonymous testing sites do not meet this criteria, We believe anonymous testing should be available at every testing site. As an individual with a long history of working with Persons Living With AIDS, I can assure you that many individuals simply will not be tested if they are cognizant that names will be reported.

Summary

You face difficult decisions. Please consider all the evidence you hear, remain open to amendments to the bill, and carry good will toward all Kansans with you into your deliberations. All of us want an end to the havoc wrought by this virus, none more so than those who experience the pain, and those who witness it. Please consider well the words of all those who testify irrespective of the journey they traveled to reach their particular expertise.

Sherry Karen Baer

Sherry Karen Baer, LSCSW

FROM THE OFFICE OF:
LIATRIS STUDER
1728 N. HOLYOKE #2
WICHITA, KS. 67208
Direct Line 316 651 0867 Email: lstuder@Hotmail.com

TO: Kansas State Legislature.. February 4, 1999
Hearings on HB 2074 (Name Based HIV Reporting)
State Capitol
Topeka, KS. 66612-1271

Honorable Legislators:

The following is my personal testimony on legislation concerning name-based HIV reporting (HB 2074). It is grounded in my education as a public health professional (Master of Public Health), work as a member of the Kansas HIV/AIDS Prevention Community Planning Group (Community Co-Chair Designate), clinic administrator, and experience as member of marginalized/stigmatized community.

There is one fact that should be clear to health professionals and legislators involved with Public Health Policy. Behavior cannot be coerced by legislation regardless of how rational or moral the basis for it may be. In and of itself, name-based HIV reporting is desirable for statistics (prevention planning and allocation of care resources), counseling, partner notification, and initiation of medical care. However issues of confidentiality and mistrust arise when communities of marginalized and oppressed minorities are involved. In order to make name-based reporting and behavior change possible, it is necessary to look beyond the behavior itself and *examine the context in which at-risk individuals make their decisions.* What may seem as irrational, unsafe and immoral from one perspective may be rational and moral from another perspective or context. Decisions with desirable outcomes can only be made when the contexts for making those decisions have been adequately addressed and improved. Name-based reporting must be seen as only one part of a total policy (or even opportunity) to change the context in which at-risk individuals make their decisions. This new context must be trustworthy, non-judgmental, and compassionate. To meet this criterion, the following issues must be addressed in any legislation regarding name-based HIV reporting:

- TRUST WORTHINESS
  Confidentiality is a must! CDC guidelines must be adhered to and the data (stripped of any identifying information) must be secure from any uses other than health research, prevention planning, and provision of care. The K.D.H.&E. Bureau of

HHS
2-4-99
Atch #12

HIV/AIDS, with input from the Kansas HIV Prevention Planning Group will be the arbiters of these uses. Violations or purposes that may result in denial of insurance coverage, implicate law enforcement (such as injection drug use), or be the basis for any other discriminatory action, will be prohibited by legislation and violation will result in severe penalties under law. Confidentiality must be seamless and extend from the point of collection to the accumulated database. Unfortunately being HIV positive carries with it a stigma that other morbidities do not share and this must be reckoned with.

- NON-JUDGMENTAL

  The language of legislation must reflect a concern for the health and welfare of all Kansans, including those at risk, and not represent moralistic posturing. Adequate anonymous testing sites must be maintained and individuals should be made aware of that option. At risk persons should not be made to feel that their character is being judged as a result of this legislation. Repeal of sodomy laws must be considered as a gesture of good faith consistent with a policy of winning the trust of at-risk communities. This is not to be a punitive (except in cases of breach of confidentiality) policy. We must also seek to get the cooperation and trust of providers who currently resist complying with AIDS reporting or may resist named HIV reporting.

- COMPASSIONATE

  The purpose of this legislation is to facilitate culturally appropriate prevention and alleviation of suffering due to HIV. It must be linked to expanded medical services and other life saving interventions such as needle exchange and drug rehabilitation programs. A decision to be tested (by an at-risk individual) under these circumstances can only be made when the context is perceived to be compassionate for the client. HIV testing may be the first contact that a wary, mistrustful, and fearful individual has with the public health system. It is essential that it be a perceived as a life affirming experience leading to better health related lifestyle decisions in the future.

Sincerely,

Liatris Studer

Liatris Studer, Community Co-Chair Designate
Kansas HIV/AIDS Prevention Community Planning Group