



**House
Legislative
Analysis
Section**

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PRIOR CONSENT FOR AIDS TESTS

House Bill 5189 as passed by the House
First Analysis (12-1-88)

Sponsor: Rep. Teola P. Hunter
Committee: Public Health

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THE APPARENT PROBLEM:

There currently is no known vaccine or cure for Acquired Immunodeficiency Syndrome (AIDS), the final, fatal stage of infection from the human immunodeficiency virus (HIV). Someone may be infected with HIV for months or even years without any overt symptoms. But once infected, one can never get rid of the virus and one can transmit it to others (in this country most commonly through sexual intercourse with an infected partner and through sharing infected drug injection equipment, such as needles). Because of this long, asymptomatic "incubation" period and because there is no vaccine or cure, much of the current effort to reduce the spread of AIDS has centered on education of the public so that individuals can modify their behavior to reduce their — and others' — risk of exposure to HIV. However, although there are good reasons for people to wish to learn their HIV status, there also are strong disincentives to being tested if the test results are not adequately protected. Fears about the disease, coupled with the absence of any known cure (and the social stigmatization of some of the behavior involved in the transmission of the virus), have sometimes given rise to abusive and even illegal action against HIV-infected individuals. One of six legislative recommendations by the AIDS Subcommittee of the House Public Health Committee addresses this problem.

THE CONTENT OF THE BILL:

The bill would add a new part, "Part 53. Human Immunodeficiency Virus Testing," to the Public Health Code. The new part would regulate testing for the presence of the human immunodeficiency virus (HIV) — the virus associated with acquired immunodeficiency syndrome (AIDS) — or for the presence of an antibody to HIV.

More specifically, the bill would prohibit HIV testing without the prior written, informed consent of the test subject (or that of his or her legally authorized representative). With certain exceptions, individuals would be able to get tested anonymously. Test results would be confidential and not disclosed except by court order or under certain other circumstances. The bill also would impose civil or criminal penalties on people who illegally disclosed HIV test results.

Informed consent. Before a physician (or someone delegated by the physician) ordered an HIV test, he or she would be required to give the subject a copy of a DPH informational pamphlet (described below), to inform the test subject of the availability of anonymous testing at DPH-designated testing sites (and the location of at least one of these sites), and to tell the subject of the bill's requirements generally (some of this information would be contained on the informed consent form included in the pamphlet).

Informed consent, for the purposes of the bill, would consist of a written consent form, signed by the test subject. The consent form would have to include, at a minimum, (a) an explanation of the test (including the purpose of the test,

its potential uses and limitations, and the meaning of test results) and (b) an explanation of the test subject's rights (including the right to change his or her mind about having the test done, the right to have the test results remain confidential, and the right to be tested anonymously). The consent form would be part of an informational pamphlet developed and distributed by the Department of Public Health (DPH).

Informational pamphlet. Within 90 days of the effective date of the bill, the DPH would have to develop an informational pamphlet on HIV testing which would include, in addition to a standard consent form, information on the purpose and nature of the test, the consequences of taking and not taking the test, the meaning of test results, and any other information the department believed to be necessary or relevant. The pamphlet would be distributed free upon request to physicians (who would have to be notified within 100 days after the bill took effect by their medical or osteopathic board of the bill's requirements and of the pamphlet's availability) by the health department and by the medical and osteopathic boards. Within 120 days after the bill took effect, any physician ordering an HIV test would be required to give the test subject a copy of the pamphlet. Test subjects given a copy of the pamphlet would be required to sign a form to that effect, which would then be added to his or her medical record. Someone who had signed a form indicating that he or she had been given a copy of the pamphlet could not then sue the physician ordering the test for failure to obtain informed consent.

The pamphlet would be available both in simple English and in Spanish, and would be available free, upon request, to public or private schools, colleges, and universities, and at cost to anyone else.

Anonymous testing and exceptions. With certain exceptions, an individual would be able to be tested anonymously, giving consent through a coded system which would not link the subject's identity with the request for an HIV test or with its results. A person could not be tested anonymously if he or she:

- (a) were donating a body organ or fluid (including blood and semen),
- (b) were part of a research project where the researcher did not know the identity of the test subject and the subject did not know the test results,
- (c) were legally required to be tested, or
- (d) were a prisoner in a county jail or a state correctional facility.

Confidentiality of test results and exceptions. The results of an HIV test would be confidential and could not be disclosed, except to the test subject, in cases of positive test results where the physician involved knew of partners of the HIV-infected patient, cases where health care or emergency personnel came into direct contact with

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HIV-infected patients, upon court order, or in accordance with law.

More specifically, test results could be disclosed to the following people under the following circumstances:

(a) The test subject (or his or her authorized representative) or anyone designated by the subject on a release form;

(b) Positive test results, identifiable partners at risk, and physician duty to warn. One exception to the confidentiality of test results would be in cases of positive test results where the physician involved knew the identities of partners (either sexual or needle-sharing) of the HIV infected patient. In these cases, physicians would be required to request that the patient tell his or her partners within two weeks of the positive test results and then to report back to the physician that the patient had done so. If the patient did not tell his or her partners, the physician would be required either to make "reasonable efforts" to notify these partners directly or else to notify the local health department. The physician would have only to make a "reasonable" effort to contact an infected patient's partner(s) and would not be required "to inquire about individuals who may be at risk of HIV infection because of their relationship with that test subject." As an alternative to trying to contact a patient's partners directly, the physician could instead contact the appropriate person in the local health department and tell that person without revealing the patient's identity — of the patient's positive test result and the identities of the "at risk" partners.

(c) Direct contact with HIV-infected patients, body parts, or fluids. Test results also would be revealed upon request to a number of other people in cases where they had direct contact with HIV-infected patients or with body parts or body fluids of HIV-infected people:

- a health care provider or employee of a health care facility who had direct contact with HIV-infected patients or who handled specimens of body fluids or tissues of HIV-infected patients;
- a health care facility or provider who handled either HIV-infected cadaver parts during the course of medical research or semen (for artificial insemination) or blood (for transfusion) from an HIV-infected donor;
- emergency personnel (police officers, fire fighters, ambulance attendants, emergency medical technicians, and others) who came into contact with the blood or other body fluids of an HIV-infected emergency patient in the course of transporting the patient to a health facility, if the test results were disclosed by someone working for the health facility;

(d) In addition to the above exceptions, the bill also would authorize releasing test results upon request to the Department of Public Health (or an agency designated by the department) and to health facility medical staff committees, for monitoring, evaluation, or service reviews;

(e) If the test results were held by a county sheriff or the warden of a state correctional facility, they could be released to anyone that the sheriff or warden decided needed to know the results;

(f) Finally, the results would be released if specifically authorized by law or if someone asked for, and was granted, a court order for their release.

Court-ordered release of test results. The bill would allow a court to order HIV test results be released if the court found that the person seeking test results had

demonstrated a compelling need for them which could not be accommodated in any other way. In deciding on whether a "compelling need" existed, the court would be required to weigh the need for disclosure against the privacy interest of the test subject and the public interest of assuring an adequate supply of human organs and tissues for donation and the confidentiality of test results. In pleadings for court-ordered disclosure of test results, a pseudonym would have to be substituted for the actual name of the test subject; disclosure of the test subject's actual name would be made confidentially to the parties in documents not filed with the court. Before granting an order compelling the disclosure of test results, the court would be required to provide the individual whose HIV test result was in question with notice and a reasonable opportunity to participate in the proceedings, if the individual were not already a party. Court proceedings would be conducted in private ("in camera"), unless the test subject agreed to an open court hearing, or unless the court determined that an open court hearing was necessary to the public interest and the proper administration of justice. When the court ordered the disclosure of test results, it also would impose appropriate safeguards against unauthorized disclosure. These would specify the people who might have access to the information, the purposes for which the information could be used, and prohibitions on future disclosure of the information.

Penalties for breach of confidentiality. Under the bill, disclosure of test results by governmental employees would carry criminal penalties; others would be liable to civil damages.

More specifically, anyone employed by, or under contract to, a governmental entity who disclosed confidential information in violation of the bill's requirements would be guilty of a felony, punishable by imprisonment for not more than three years, or a fine of not more than \$5,000, or both.

Anyone else who disclosed confidential information in violation of the bill's requirements would be liable in a civil action for actual damages or \$5,000 (whichever was greater), punitive damages, and costs and reasonable attorney fees. These penalties also would apply to such a person's employer, unless the employer had put in place reasonable precautions to prevent employees from disclosing the results of an HIV test.

MCL 333.1101 et al.

FISCAL IMPLICATIONS:

The House Fiscal Agency estimates that it would cost the DPH \$337,500 to develop, print, and distribute the informational pamphlet required by the bill. Additional unknown costs would be incurred by local health departments, if they did contact tracing under the "duty to warn" section of the bill. (12-5-88)

ARGUMENTS:

For:

The bill would encourage testing for HIV infection by guaranteeing that all such testing could be done only with the written informed consent of the test subject and by allowing most people the option of being tested anonymously. The confidentiality provisions are backed by strong penalties for breach of confidentiality, with the exceptions being only those necessary for specific (and in most cases, public health) "need to know" cases.

Against:

While the concept of the bill — written informed consent prior to HIV testing, the availability of anonymous testing, and strict confidentiality of test results — is admirable, the numerous exceptions, both to anonymous testing and to confidentiality, must inevitably result in "leaks" and in the kind of public "backlash" treatment that HIV-infected people rightly fear. A survey conducted by the Association of State and Territorial Health Officials (ASTHO) reported in June, 1988, that there had been at least 75 cases of AIDS-related breaches of confidentiality (usually involving release of a patient's name and diagnosis by hospital staff members — both medical professionals and clerical staff — either to an employer or to the media) and 233 acts of AIDS-related discrimination (though the New York City Commission on Human Rights alone reported receiving 614 AIDS-related discrimination cases between January 1986 and June 1988). Breaches of confidentiality often disrupted the person's family or living situation and sometimes led to the loss of a job or an inability to get medical care. ASTHO recommended that HIV antibody test results be released only with the consent of the person tested and that states adopt laws barring release of name-linked information under subpoena or court order.

Response: The ASTHO report also said that most of the AIDS-related discrimination cases followed a voluntary disclosure, which means breach of confidentiality wasn't even involved. The report also did recommend that HIV testing be preceded by counseling and informed consent (written, informed consent would be required by the bill), that testing counselors should tell people about the possible repercussions of revealing their HIV status, and that health care providers and agencies develop policies to assure confidentiality.

POSITIONS:

The Department of Social Services is not taking a position on any specific AIDS bill, but adopted an "HIV Infection Position Paper" which "endorses pretest and post-test . . . counseling and testing . . . offered on a voluntary, confidential, and anonymous basis." The paper also says that "DSS agrees . . . that mandatory partner notification should not be pursued and that a voluntary partner notification system should be utilized. Assurances need to be made, reinforced by strict penalties, that confidentiality of all involved is maintained." (11-15-88)

The Hemophilia Foundation of Michigan supports the general availability of anonymous testing. (11-30-88)

The Michigan Organization for Human Rights opposes the bill. (11-29-88)

The Michigan Chapter of the National Organization of Women opposes the bill. (11-30-88)