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Testimony on Senate Bill 1261
before the
Pennsylvania Senate Committee on Public Health and Welfare

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Chairman Erickson and other members of the Committee on Public Health and Welfare:

Good morning. My name is Ronda Goldfein, and I am the executive director of the AIDS Law Project of Pennsylvania. I would like to thank Senator Erickson and the other members of the Committee for this opportunity to share my concerns about Senate Bill 1261, the most significant piece of HIV-related legislation in the Pennsylvania General Assembly in almost two decades.

At the AIDS Law Project of Pennsylvania we see how people with HIV/AIDS are fighting not only a disease, but also for the right to be treated fairly in society. Although the extent and depth of HIV stigma and discrimination has decreased since Act 148 was adopted 18 years ago, we continue to receive three to five complaints of discrimination every week. These complaints are from people who have been treated differently, often unlawfully, simply because they have a virus. This problem is not limited to Pennsylvania; it has been well-documented elsewhere as well.

I also represent the HIV Policy Collaborative of Pennsylvania, an association of about 20 community-based AIDS service organizations providing assistance to people with HIV/AIDS and their families. The group is an integral part of the effort to prevent HIV transmission throughout Pennsylvania. The feedback we have received from our member organizations is strongly against amending Act 148 in the form of Senate Bill 1261.

I believe that we – the AIDS Law Project; the member organizations of the HIV Policy Collaborative; Senator Erickson and the members of the committee; and the highly committed health-care professionals who are here to testify today – all share the commitment to fighting HIV/AIDS, by reducing and some day ending transmission of HIV.

But that can only be done while still protecting the rights of those living with the disease.

A critical step in reducing the transmission of HIV is for people with HIV to know that they are infected. We need to assure that HIV testing is offered and readily available to anyone who may be at risk.

Testing positive for HIV is not only a means of reducing future cases of HIV, but is also the first step in getting life-prolonging health care for people with HIV. Testing positive has such a profound impact on an individual, both psychologically and socially, that patients must be equal, informed partners in the health care decisions that affect them.

The Centers for Disease Control and Prevention (CDC)'s 2006 recommendation of universal opt-out testing in an effort to streamline testing is well-intentioned, as is Senate Bill 1261. Opt-out screening, however, can diminish a patient's ability to give informed consent, which is a fundamental element of all health care.

People – particularly those who are timid, intimidated by medical authority, or overwhelmed by the swift pace with which many exams are conducted – might not receive an explanation of what the test is or why it is appropriate for them. Patients may not even realize that they have been tested until the results come back.

I sympathize with the frustrations of health-care providers who want to increase HIV testing for their "at risk" patients, but Act 148 is not the problem. Our state law contains clear requirements for HIV testing – pre-testing counseling, written informed consent and face-to-face post-test counseling – that, when implemented properly, are *not* barriers to testing.

I believe the CDC's goal of expanding and streamlining HIV testing can easily be accomplished through the development of three initiatives that are consistent with existing law.

1. Encourage health-care providers to offer HIV testing for all patients, consistent with sound professional judgment. Offering the test to all patients will reduce the stigma of being targeted for testing on the basis of the patient's identifiable risk factors or on the basis of demographic factors;

2. Develop consent forms that contain sufficient pre-testing counseling information so that the patient can make an informed decision and a signature line that proves the patient consented. The Family Planning Council, a network of 27 family planning provider agencies throughout Southeastern Pennsylvania, has already developed an HIV testing policy, including a consent form, which provides information about the test and is signed by the patient.

3. Advocate for HIV screening, including the HIV antibody test and confirmatory testing, to be defined as a routine part of preventive medical care and covered by private and/or government health insurance.

These initiatives were discussed at length at a February 13-14, 2008 meeting convened by the Pennsylvania Department of Health to look at the CDC's recommendations in light of Act 148. This meeting, which included a broad range of Act 148 stakeholders, did not result in any consensus regarding amendment of Act 148. The stakeholders also identified the Pennsylvania/Midatlantic AIDS Education and Training Center, the regional center of a national program that conducts targeted, multidisciplinary education and training programs for health care providers treating persons living with HIV/AIDS, as a resource to develop these initiatives.

The AIDS Law Project of Pennsylvania and the HIV Policy Collaborative of Pennsylvania are opposed to Senate Bill 1261's incorporation of the CDC's recommendation that HIV testing be streamlined by dispensing with the requirement of HIV-prevention counseling prior to testing. Removing the pre-test counseling requirement, without clarifying the information necessary for informed consent, provides even less patient protections than the CDC's recommendation, which explicitly includes the importance of discussion opportunities before testing. Pre-test counseling information may be written, instead of verbal, as long as a counselor is available if the patient has questions or the provider is uncertain whether the patient understands the consent.

Although Senate Bill 1261 retains Act 148's informed-consent requirement, both by retaining reference to it in the legislative-intent section and in the consent-for-testing section, it deletes Act 148's mandate that the patient's written informed consent be obtained before testing. Senate Bill 1261 also allows the consent to be documented by the health care professional, instead of by the patient.

The best way, however, to provide and document informed consent is through a consent form, signed by the patient. HIV tests are not unique in requiring written informed consent. A Pennsylvania patient must sign a consent form before receiving treatment for breast disease, obtaining an abortion, replacement of dental amalgams, any surgery, administration of anesthesia, treatment in birth centers, and certain psychiatric treatments. This form ensures that the patient was not tested without first getting sufficient information, so that he or she can make an informed decision about whether to proceed.

Pennsylvania has a strong law that protects its citizens, which is compatible with the spirit of the CDC's recommendations. The law should not be discarded lightly. Many other states have also kept their HIV laws intact since the CDC announced its recommendations for HIV testing in health-care settings in 2006. After two years, the CDC's recommendations have not received anything close to widespread endorsement by state lawmakers.

Most notable among those as HIV high-incidence states that have changed their laws in response to the CDC recommendation are California and Illinois. Both states, however, while dropping the written-consent requirement, retained the informed-consent standard. Perhaps more significantly, both California and Illinois have (unlike Pennsylvania's Act 148) effective enforcement provisions. Both states provide criminal and civil penalties for violations. In Illinois, those provisions were strengthened at the same time as the written-consent requirement was dropped.

If Act 148 is to change, then the amended law should contain sections on universal-offer testing; private and/or government health-insurance coverage for HIV screening; and enhanced remedies for any violation of the testing or confidentiality provisions. Specific damage amounts should be included for intentional, reckless or negligent violations of the statute, as well as attorneys' fees and costs.

Many here today may remember a time when cancer was subject to the same fears and biases now directed toward HIV. Newspaper obituaries wouldn't even list cancer as a cause of death. To make real progress in this epidemic, HIV needs to be mainstreamed the same way cancer has been, but done in a way that reduces the stigma and that does not "mislead" people into testing. Only with the full participation of the patient in treatment decisions will we see a reduction in the stigma fueling this epidemic.

I ask that the Committee recognize that, without proof of informed consent, patient involvement in testing and treatment decisions will be diminished and we will have taken a giant step backward in the fight against HIV/AIDS.

AIDS prevention occurs when people are encouraged to take responsibility for their own decisions. Thank you very much.