



ALCC

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Dr. Eric E. Whitaker, Director
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Dear Director Whitaker:

I am writing on behalf of the AIDS Legal Council of Chicago to express our strong position in opposition to any mandatory HIV testing of newborns in Illinois and in particular, to H.R. 4306 which Rep. Mary Flowers has introduced.

Written informed consent has been the cornerstone of our state's approach to HIV testing since the Illinois legislature first addressed the issue in the AIDS Confidentiality Act almost two decades ago. That law states, "No person may order an HIV test without first receiving the written informed consent of the subject of the test or the subject's legally authorized representative." (410 ILCS 305/4) The legislature explicitly outlined the reasons for such care and deliberation in its legislative findings:

Despite existing laws, regulations and professional standards, which require or promote the informed, voluntary and confidential use of tests designed to reveal HIV infection, many members of the public are deterred from seeking such testing because they misunderstand the nature of the test or fear that test results will be disclosed without their consent. **The public health will be served by facilitating the informed, voluntary and confidential use of tests designed to reveal HIV infection.** (410 ILCS 305/2, emphasis added).

Written informed consent, which under Illinois law includes the right to refuse an HIV test, is vital to keeping people at risk for HIV engaged with the health care system – and in particular the public health care system. When supported by strong confidentiality requirements, as Illinois law mandates, it is the most effective way to assure that people concerned about their HIV status will readily avail themselves of testing.

Currently no class of Illinois citizens can be tested for HIV without written, informed consent. Yet if the proposed amendment to the Perinatal HIV Prevention Act becomes law, women who have newly delivered babies will be stripped of a legal right that every other group enjoys. Such a move would make for bad law as well as bad public health policy.

The Perinatal HIV Prevention Act requires health care professionals to provide HIV counseling and offer HIV testing to pregnant women in their care (410 ILCS 335/10(a)). Further, it requires health care professionals to provide HIV counseling to a woman whose HIV status is unknown within 48 hours of the birth of her child, and to perform HIV testing on her newborn provided she does not refuse the testing. (410 ILCS 335/10(c)). It goes on to say that, in accordance with HIV testing for all other citizens under the AIDS Confidentiality Act, she must be informed of her right to refuse the test (410 ILCS 335/10(d)(5)).

The goal of this legislation, a goal shared by all reasonable advocates concerned about perinatal HIV infection, is to reduce HIV in newborns. But it is vital to understand that an HIV test on a newborn does *not* reveal that child's HIV status, since babies do not develop their own system of immune response until months after delivery. The test can only reveal the *mother's* HIV status, and indicate the *possibility* that the infant has HIV.

Still, this information can be vital to mothers and medical providers, which is precisely why the current Perinatal HIV Prevention Act requires mothers be thoroughly counseled and that HIV testing of her newborn be made immediately available. But if after such counseling, a new mother still declines to have her newborn tested for HIV (which, it is important to remember, is in truth a test for her own HIV status), she surely has a very good reason to do so. The test results, showing that her child has been exposed to HIV, will be available to that child's father. Perhaps the father is abusive, and she knows that his violence against her – and perhaps against her baby – will escalate if she is revealed to be HIV positive. Perhaps she has seen another family member ostracized after learning of his or her HIV status, and the last thing she needs with a newborn baby is have her family kick her out of the house. Perhaps she is already distrustful of the public health system, having heard stories of forced sterilizations against women like her in the not-too-distant past, and no amount of assurances to the contrary will allay her fears. This is a woman the public health system can scarce afford to further alienate; if the coerced HIV test on her baby comes out positive, there is a real risk that she will never return for the care she desperately needs.

The decision to test a newborn for HIV, and thereby to test the baby's mother as well, must take into account the social and economic stressors the mother faces, stressors only the mother can accurately assess. Her safety and well-being bear directly on future health of her baby. To assume that testing a newborn for HIV is the best idea in every situation is to practice medicine in a vacuum, and potentially to put a mother and her baby in harm's way.

Creating mandatory newborn testing also effectively removes from pregnant women the ability to make their own informed decisions about HIV testing during pregnancy or during labor and delivery. A woman's present right to refuse testing, for all the reasons mentioned above, becomes meaningless if the health care system will determine her HIV status after she delivers whether or not she consents to the earlier testing. Illinois will then be saying that testing will happen only with informed consent—except for 200,000 pregnant women each year, who will instead face *de facto* mandatory testing.

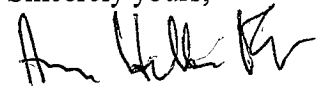
In addition to the taking away from pregnant woman a fundamental right to decide for herself

whether to be tested for HIV, the proposed legislation pushes the perinatal HIV prevention focus away from where it is most effective—pregnancy and labor and delivery-- and toward where it is least effective—after birth. The Perinatal HIV Prevention Act puts the focus where it should be: reaching the woman as early in pregnancy as possible with effective counseling and testing. The first year's implementation of that new Act, with the Department's support, has been extremely successful. The systems that hospitals have put in place are working. Pregnant women in those systems are treated with respect and dignity and have responded, almost unanimously, with decisions that are best for them and for their babies. There is no question that the Prevention Act has effectively reduced perinatal HIV transmission to extremely low levels, and that the number of infected infants continues to decrease as the systems mature. To create an entirely new program, in which hospitals must develop new protocols focusing on the rapid testing and treatment of newborn infants, can only detract from the demonstrable success of the present law, to the inevitable detriment of both mothers and their children. .

We have heard that the Department has already agreed to support mandatory testing of newborns. We hope we have heard incorrectly. The Department should be taking pride in the success of the Perinatal HIV Prevention Act implementation and looking for ways to institutionalize and improve on that success. The Department should not be undermining that success by putting its efforts and credibility behind a program that will instead focus on less-effective interventions. Voluntary testing with informed consent has been one of the cornerstones of the fight against HIV in Illinois. We know that it is effective in preventing perinatal transmission of HIV. It should not lightly be set aside.

Please feel free to contact me if I can provide any further information.

Sincerely yours,



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