The Honorable Tom A. Coburn, M.D.
United States Senate
172 Russell
Washington, D.C. 20510

Re: HIV testing during pregnancy in Connecticut

Dear Senator Tom A. Coburn:

In response to your letter dated March 23, 2006, please find attached a copy of the statutes to which HIV testing for pregnant women and newborns was added in 1999. Prior to this legislation, prenatal care providers were required to counsel pregnant women about the benefits of HIV testing. The 1999 legislation builds on this requirement, adding two voluntary tests during the prenatal period with testing offered again at delivery for patients that decline. HIV testing is mandatory for the newborn if maternal HIV status is unknown at the time of delivery.

Your letter raises a number of specific questions that are addressed below.

Would you deem it a success? Appropriate HIV testing during pregnancy is an essential component in the prevention of perinatal HIV transmission. The 1999 legislation has had a dramatic impact on the rate of HIV testing in pregnant women in Connecticut. Prior to the legislation, 28% of prenatal records included documentation of HIV testing. At the same time testing rates for other infectious diseases including hepatitis B, syphilis and rubella were over 95%. With the enactment of this legislation, the HIV testing rate increased to 90% by two months after implementation. A study is currently being conducted to assess the prenatal testing rate for children born in 2003.

Has it enabled you to better identify and provide treatment to more women with HIV and children at risk for infection? The legislation ensures that all pregnant women and their providers have the best opportunity to learn about HIV infection in time to start treatment and also to take advantage of other prevention measures, such as appropriate use of Cesarean section and restriction on breastfeeding. During 1996-2004, 50-70 HIV-positive pregnant women delivered each year in a birth cohort of approximately 42,000 (1.2-1.7 per 1,000 births) (source: HIV surveillance). Approximately 60% of cases were known to be HIV positive prior to pregnancy both before and after legislation. Before legislation, however, 24% of HIV-positive women received their first diagnosis during pregnancy but this increased to 34% after the law was implemented with fewer women being identified at or after delivery (5% before the legislation to 1% after). For 5%-10% of cases, time of diagnosis could not be determined. However, the legislation has also been particularly important in cases where testing might not happen if it was based on risk assessment only. This includes cases where there is little or no
perception of risk on the part of the patient/provider, and where the patient is not forthcoming about her risk or is unaware of her sex partner's risk. Although it happens infrequently, we have also learned that in some cases, an unexpected positive test has resulted in further testing in the family with identification of other HIV-infected persons, such as sex partners and other children.

Has there been any evidence that this law has discouraged women from seeking prenatal care? The results from a survey of obstetricians conducted in 2001 (asking about their experiences in 2000, the first full year after the law was implemented), suggested that they perceived little negative impact on their practices/patients (~90% response rate among prenatal care providers). For example, 84% indicated that the legislation had no impact or a positive impact on their practice/patients. An additional 6% indicated that the legislation had both positive and negative effects (6% indicated negative impact and 5% did not answer). Negative comments generally mentioned increased costs and time required for counseling. Conversely, however, many providers indicated that having the legislation facilitated testing. An analysis of birth record data for 2000 indicated that there was no significant overall decline in the number of prenatal visits or month of gestation at which prenatal care began.

What was the number of newborns with HIV/AIDS recorded annually prior to the law and in the most current year for which you have data? The number of HIV-positive newborns reported to the Department is the following: 1996=6 (of 67 exposed children); 1997=3 (69); 1998=1 (64); 1999=5 (70); 2000=1 (75); 2001=4 (68); 2002=0 (63); 2003=0 (50); 2004=0 (57). Final status cannot be determined for some children ranging from 1.4% to 22.0% of exposed children in a given year. While this can change with late reports, it is noteworthy that no HIV-infected newborns have been reported who delivered during 2002-2004. We would not attribute this progress entirely to the legislation but a high testing rate is prerequisite to a low transmission rate. Other factors play a role as previously mentioned, including progress that is being made in treatments that can reduce HIV viral load to a very low level thus reducing the risk inherent in blood exposure at delivery.

What percentage of pregnant women refused HIV testing? In the 2001 survey of obstetricians, 40% of respondents indicated that no patient had refused testing subsequent to the legislation, 44% indicated less than 3% of patients had refused testing, 8% indicated that 3-10% of patients refused, and 8% did not answer the question. In the year in which this survey was conducted, HIV testing was still controversial and there was likely some continuing adjustment in prenatal care provider practices and among pregnant women. In the years since enactment, the controversy surrounding the legislation has moderated significantly.

What are their reasons for refusing testing? Information about this was not collected as part of the survey of obstetricians. Anecdotally, we have been told that perception of low risk is a motivator in refusing testing. However, perception of risk seems to be HIV specific in that many fewer women have syphilis infection during pregnancy and that is not a test that is resisted.

What percentage of newborns and new mothers are sent home after delivery with an unknown HIV status? How does this compare to the percentage prior to the enactment of the law? Answering this question accurately would require an assessment of newborn records, which has not been done. The newborn testing provision of the legislation is meant to ensure that maternal HIV status is known for every pregnant woman. Although not part of the legislation, rapid
testing protocols have been implemented in all Connecticut hospitals with maternity services to ensure that HIV status is determined for pregnant women who have not had prenatal care or who may have previously declined testing.

*What percentage of women and children that test positive for HIV antibodies are then referred into appropriate care?* All HIV-positive women and their exposed newborns are referred to appropriate care. Patient compliance can occasionally be a problem for a number of reasons and in areas that are distant from tertiary care centers that specialize in HIV treatment, travel to the care center can create barriers to following through on referrals.

Finally, a comment about whether the legislative approach to increasing testing is preferred to education of providers and patients. The periodic assessments of testing rates for infectious diseases that have been conducted by the Department have shown that while the testing rate for hepatitis B increased from 52% to 95% in response to educational activities over a four-year period (1990-1993), the testing rate for HIV remained constant at 28% for four years (1996-1999) prior to the legislation.

If you have any other questions with respect to this matter, please do not hesitate to contact Aaron Roome, PhD, Supervising Epidemiologist, HIV/AIDS Surveillance Program. He may be reached at 860-509-7900.

Sincerely,

[Signature]

J. Robert Galvin, MD, MPH
Commissioner

19a-593 establishes that all pregnant women must receive HIV counseling during prenatal care and that if testing is refused on admission for delivery it must be in writing.

Sec. 19a-593. Testing of pregnant women and newborns.
(a) Each health care provider giving prenatal care to pregnant women in this state shall inform her, or ascertain from the woman's medical record that such information has already been provided to her, that HIV testing is a part of routine prenatal care and shall inform her of the health benefits to herself and her newborn of being tested for HIV infection. Such information shall be conveyed along with the counseling required by section 19a-582. The health care provider shall inform the patient that HIV-related information is confidential pursuant to section 19a-583. If the patient provides informed consent to an HIV-related test consistent with section 19a-582, the health care provider responsible for HIV counseling under this section shall perform or arrange to have performed an HIV-related test and document the test result in the medical record.
(b) If, during the current pregnancy, an HIV-related test has not been documented in the patient's medical record at admission for delivery of the baby, then the health care provider responsible for the patient's care shall inform the pregnant woman as required under subsection (a) of this section and shall also inform her of the health benefits to herself and her newborn of being tested for HIV infection either before delivery or within twenty-four hours after delivery and, in the absence of specific written objection, shall cause such test to be administered.
History: June Sp. Sess. P.A. 99-2 deleted existing provisions requiring obstetrician-gynecologists to notify pregnant women of the availability of AIDS testing, added Subsec. (a) re information on HIV testing, performance of HIV testing and documentation of test results, and added Subsec. (b) re HIV information and testing at admission for delivery.
See Sec. 19a-55 re newborn infant health screening.
See Sec. 19a-90 re blood test of pregnant women.
19a-90 establishes that HIV testing must be offered twice during prenatal care, once early in pregnancy and once during the third trimester, consistent with syphilis testing.

Sec. 19a-90. (Formerly Sec. 19-47). Blood testing of pregnant women for syphilis and AIDS. 
(a) Each physician giving prenatal care to a pregnant woman in this state during gestation shall take or cause to be taken a blood sample of each such woman within thirty days from the date of the first examination and during the final trimester between the twenty-sixth and twenty-eighth week of gestation or shortly thereafter subject to the provisions of this section, and shall submit such sample to an approved laboratory for a standard serological test for syphilis and an HIV-related test, as defined in section 19a-581, provided consent is given for the HIV-related test consistent with section 19a-582. Each other person permitted by law to attend upon pregnant women in the state, but not permitted by law to take blood tests, shall cause a blood sample of each pregnant woman so attended to be taken by a licensed physician in accordance with the time schedule and requirements of this section and such sample shall be submitted to an approved laboratory for a standard serological test for syphilis and an HIV-related test, provided consent is given for the HIV-related test consistent with section 19a-582. A blood sample taken at the time of delivery shall not meet the requirement for a blood sample during the final trimester. The term "approved laboratory" means a laboratory approved for this purpose by the Department of Public Health. A standard serological test for syphilis is a test recognized as such by the Department of Public Health. The laboratory tests required by this section shall be made on request without charge by the Department of Public Health.

(b) The provisions of this section shall not apply to any woman who objects to a blood test as being in conflict with her religious tenets and practices.


History: P.A. 77-614 replaced department of health with department of health services, effective January 1, 1979; P.A. 79-39 simplified language and required blood sample taken during final trimester of pregnancy; Sec. 19-47 transferred to Sec. 19a-90 in 1983; P.A. 90-13 amended Subsec. (a) to specify that the test during the final trimester be done between the twenty-sixth and twenty-eighth week of gestation and added Subsec. (b); P.A. 93-381 replaced department of health services with department of public health and addiction services, effective July 1, 1993; P.A. 95-257 replaced Commissioner and Department of Public Health and Addiction Services with Commissioner and Department of Public Health, effective July 1, 1995; June Sp. Sess. P.A 99-2 added HIV-related test requirement in Subsec. (a).

See Sec. 19a-55 re newborn infant health screening.
See Sec. 19a-215 re required reporting of communicable diseases.
See Sec. 19a-593 re testing of pregnant women and newborns.
Sec. 19a-55. (Formerly Sec. 19a-21b). Newborn infant health screening. Tests required. Fees. Regulations. Exemptions. (a) The administrative officer or other person in charge of each institution caring for newborn infants shall cause to have administered to every such infant in its care an HIV-related test, as defined in section 19a-581, a test for phenylketonuria and other metabolic diseases, hypothyroidism, galactosemia, sickle cell disease, maple syrup urine disease, homocystinuria, biotinidase deficiency, congenital adrenal hyperplasia and such other tests for inborn errors of metabolism as shall be prescribed by the Department of Public Health. The tests shall be administered as soon after birth as is medically appropriate. If the mother has had an HIV-related test pursuant to section 19a-90 or 19a-593, the person responsible for testing under this section may omit an HIV-related test. The Commissioner of Public Health shall (1) administer the newborn screening program, (2) direct persons identified through the screening program to appropriate specialty centers for treatments, consistent with any applicable confidentiality requirements, and (3) set the fees to be charged to institutions to cover all expenses of the comprehensive screening program including testing, tracking and treatment. The fees to be charged pursuant to subdivision (3) of this section shall be set at a minimum of twenty-eight dollars. The commissioner shall adopt regulations, in accordance with chapter 54, specifying the abnormal conditions to be tested for and the manner of recording and reporting results. On or before January 1, 2004, such regulations shall include requirements for testing for amino acid disorders, organic acid disorders and fatty acid oxidation disorders, including, but not limited to, long-chain 3-hydroxyacyl CoA dehydrogenase (L-CHAD) and medium-chain acyl-CoA dehydrogenase (MCAD).

(b) The provisions of this section shall not apply to any infant whose parents object to the test or treatment as being in conflict with their religious tenets and practice.


History: P.A. 77-614 replaced department of health with department of health services, effective January 1, 1979; P.A. 78-193 included tests for hypothyroidism and galactosemia and transferred regulation power from department to commissioner; Sec. 19-21b transferred to Sec. 19a-55 in 1983; P.A. 92-227 amended Subsec. (a) to add sickle cell disease, maple syrup urine disease, homocystinuria and biotinidase deficiency to list of diseases for infant testing and to detail responsibilities of the commissioner in administering the program; P.A. 93-381 replaced department of health services with department of public health and addiction services, effective July 1, 1993; P.A. 95-257 replaced Commissioner and Department of Public Health and Addiction Services with Commissioner and Department of Public Health, effective July 1, 1995; June 18 Sp. Sess. P.A. 97-8 added congenital adrenal hyperplasia to the list of diseases tested for; June Sp. Sess. P.A. 99-2 amended Subsec. (a) by replacing "infants twenty-eight days or less of age" with "newborn infants", adding HIV-related test, adding provision that tests be administered as soon after birth as is medically appropriate and that test may be omitted if done under other statutes, and adding "consistent with any applicable confidentiality requirements" in Subdiv. (2); P.A. 02-113 amended Subsec. (a) to add requirement for testing of "other metabolic diseases", to add a minimum fee requirement of twenty-eight dollars, and to add requirement that on or before January 1, 2003, the regulations shall include testing for amino acid disorders, organic acid disorders and fatty acid oxidation disorders; June 30 Sp. Sess. P.A. 03-3 amended Subsec. (a) by changing date for regulations requiring testing for certain disorders from January 1, 2003, to January 1, 2004, effective August 20, 2003.