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BILL ANALYSIS

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**Senate Bill 162 (as enrolled)**

Sponsor: Senator Vern Ehlers

Committee: Health Policy

Date Completed: 4-14-87

**RATIONALE**

Since 1965, the Public Health Code has required that newborn infants be tested for phenylketonuria (PKU), a rare disorder that can cause severe, irreversible brain damage. Newborn infants also have been tested, since the early 1980s, for hypothyroidism, galactosemia, and biotinidase deficiency by using the same blood test that detects PKU. Last year, the Legislature enacted Public Act 300 of 1986 to expand the mandatory testing to detect these disorders as well as maple syrup urine disease, sickle cell anemia, and "other treatable but otherwise handicapping" conditions as designated by the Department of Public Health. The Department reports that it will not be ready to implement the Act by its effective date of March 31, 1987. Although, in practice, the Department already tests at least 85% of the newborns in the State, with the remaining tests processed through hospital labs, the Act does not provide the Department with the spending authority or funding to purchase equipment and hire personnel. Extending the effective date and providing a fee for each test, some people argue, would give the Department the funds and time it needs to obtain the equipment and train personnel in order to implement the Act.

**CONTENT**

The bill would amend the Public Health Code to provide an effective date of July 1, 1987, for the existing requirement that health care professionals in charge of the care of newborn infants, or in charge at the birth of infants, administer or cause to be administered a test for galactosemia, hypothyroidism, maple syrup urine disease, biotinidase deficiency, sickle cell anemia, and "other treatable but otherwise handicapping conditions" as designated by the Public Health Department. Under the bill, the Department also could require that the test be "performed" by the Department. If the Department performed a test, it could charge a fee for the test of not more than \$18. This amount would have to be adjusted annually by an amount determined by the State Treasurer to reflect the cumulative annual percentage change in the Detroit Consumer Price Index. The Department would be required to provide for a hardship waiver of the fee, under circumstances "found appropriate" by the Department.

"Detroit Consumer Price Index" would mean the most comprehensive index of consumer prices available for the Detroit area from the U.S. Department of Labor's Bureau of Labor Statistics.

MCL 333.5431

**BACKGROUND**

The legislative mandate for newborn screening for metabolic diseases that cause mental impairment began in Michigan in the fall of 1965. The development of a blood

spot test (called the Guthrie test) permitted recognition and treatment, using special formulas, in infancy for PKU. Nearly 300 infants, or one in 10,000 births, have benefited from this procedure after testing 2.4 million babies in the State. In 1980, without legislative mandate, congenital hypothyroidism, which occurs in one in 5,000 births, was added to newborn screening along with a test for galactosemia, which occurs in one in 200,000 births, both treatable causes of mental retardation. Subsequently, biotinidase deficiency, first discovered in a Michigan family, in a collaborative study was found to be a rare, one in 75,000-100,000 births, but treatable cause of newborn convulsions, death, and neurological brain damage. In 1986, the law was amended to mandate testing for these diseases along with maple syrup urine disease, which occurs in one in 150,000-200,000 births and is another cause of newborn brain damage, and sickle cell disease, which is not curable but whose complications can be prevented.

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**FISCAL IMPACT**

The bill would result in an increase in State fee revenues of approximately \$2,340,000, assuming approximately 130,000 births per year and assuming that the Michigan Department of Public Health would perform and charge \$18 each for 100% of the tests. Using the same assumptions, the bill also would result in an increase in Department laboratory costs of approximately \$467,000 in the first full year. First year costs include salaries and fringe benefits for 10 FTEs, contractual services, supplies and materials, equipment, and remodeling costs. In subsequent years, the cost of the program would be approximately \$270,000 for staff and material costs. In the event that the fee revenues were appropriated to the Department of Public Health to offset program costs, net revenues would be \$1,873,000 in the first year and \$2,070,000 in subsequent years.

**ARGUMENTS****Supporting Argument**

The Department is experiencing problems in implementing Public Act 300 by the March 31 effective date, and will need 10 weeks to purchase equipment, especially equipment designed for sickle cell anemia testing, and to train personnel to administer the test. Extending the deadline to July 1, the bill would give the Department the margin of time it needs to implement the testing program.

**Supporting Argument**

The Department has processed most of the infant blood tests in the State. Of the 300 babies that have been identified as having PKU, out of the 2.4 million babies tested, there have been only four cases in which there was an incorrect diagnosis. In those cases, PKU was diagnosed after the children were more than two years old. These

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children now are mentally retarded and nonfunctional. None of those tests took place in a State laboratory. Requiring the Department to conduct the tests would centralize the process and increase accountability.

**Response:** Proponents claim that the bill would require the Department to do the tests. Yet, the bill says the Department "may require" the test to be performed by the Department. This provision could allow the Department to contract with another entity to conduct the tests and could affect the accuracy of newborn disease detection.

### ***Supporting Argument***

The \$18 fee reflects the cost of conducting the tests. If the test were conducted commercially, it would cost more. Considering that the average cost per birth for hospital and doctors fees amounts to approximately \$2,000, the proposed fee would not be unreasonable. Further, the cost of the test would be minimal compared to the fact that early detection of these disorders can avoid death or irreversible mental retardation, and compared to the cost of caring for a mentally impaired individual.

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This analysis was prepared by nonpartisan Senate staff for use by the Senate in its deliberations and does not constitute an official statement of legislative intent.