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### THE APPARENT PROBLEM:

Currently, the Public Health Code requires all newborn infants to be tested for six treatable but otherwise handicapping conditions: phenylketonuria, galactosemia, hypothyroidism, maple syrup urine disease, biotinadase deficiency, and sickle cell anemia. Positive test results must be reported to the baby's parents or guardians, and the price of the tests is tied to the Detroit consumer price index. (When this part of the code was amended to add the last five tests to the list of required tests, the price of the tests was \$18. Since then, it has been raised to \$22.) At the request of the Michigan Association of Public Health, legislation has been proposed that would add a seventh test to the list of tests done on newborn infants for treatable but otherwise handicapping conditions.

## THE CONTENT OF THE BILL:

The bill would amend the Public Health Code to add a seventh condition, congenital adrenal hyperplasia, to the other conditions for which all newborns must be screened. It also would allow the Department of Public Health to raise the fee for the tests from the present \$22 for the six tests to \$25 for the proposed seven tests and would require the department to promulgate rules that defined a "good faith" effort to report positive test results.

MCL 333.5431

# **HOUSE COMMITTEE ACTION:**

The House Committee on Public Health added an amendment that would set a time limit on when the Department of Public Health would have to submit for promulgation the rules defining a "good faith" effort to report positive test results to parents or guardians (namely, within 90 days after the bill took effect).

### **NEWBORN TESTS AND FEES**

Senate Bill 502 with House committee amendments
First Analysis (4-6-92)

Sponsor: Sen. Vernon J. Ehlers Senate Committee: Health Policy House Committee: Public Health

#### FISCAL IMPLICATIONS:

A representative of the Department of Public Health testified before the House Public Health Committee that the fees for the tests would cover the costs of the program when combined with money left over from previous fiscal years. (4-2-92)

More specifically, the House Fiscal Agency reports that the 1991-92 public health appropriations act (Public Act 120 of 1991) appropriated \$3,973,100 in revenues from newborn genetic screening fees. In 1990-91, there were 153,524 testing cards sold by the Department of Public Health, at \$20 a card, resulting in revenues of approximately \$3,000,000. If a similar number of cards were sold in 1991-92, and the bill became effective January 1, 1992, the revenues would be approximately \$3,600,000. The difference between the appropriation and the available revenues would be funded by revenues received in previous fiscal years but not spent (approximately \$500,000 in revenues are expected to be available to carry over into 1991-92). On a fullyear basis, if a similar number of cards were sold at \$25 per care, the revenues would be \$3,800,000. If inflation between 1991-92 and 1992-93 were 4 percent, the charge would increase to \$26 and revenues would be approximately \$4,000,000. (11-7-91)

## **ARGUMENTS:**

#### For:

The current newborn screening program in the Department of Public Health is an important preventive health care program. By offering early detection, preventive treatment, and follow-up for six congenital conditions, the program results in significant health care, social, and educational savings.

Congenital adrenal hyperplasia (CAH) is an inherited defect in which the body cannot properly

synthesize a hormone produced by the adrenal glands (adrenal cortisol). Although the defect is rare, it can reliably be tested for in newborn babies and can be treated relatively inexpensively with drugs. At present, it is known to occur in about one of every 15,000 live births, which means that in Michigan between 10 and 15 children will be born with CAH every year. The majority of children affected with the severe form of the condition (known as the "salt losing" form of CAH, because it results in a salt imbalance which leads to shock) die within weeks after birth if not treated. The test for this condition is relatively inexpensive and meets the American Academy of Pediatrics' criteria for inclusion in a newborn screening program because of its relatively low cost and because, once detected, the condition can be easily treated, preventing both needless deaths and disability. Screening for CAH also should lead to earlier diagnosis of milder forms of the condition and to the earlier identification of parents who carry the abnormal gene. Successful screening programs reportedly have been in operation in several states for some time. The costbenefit ratio of preventive testing of newborn babies makes good public health sense and good fiscal sense.

# **POSITIONS:**

The Department of Public Health supports the bill. (4-2-92)

The Departments of Pediatrics at Borgess Medical Center and Bronson Methodist Hospital support the bill. (4-6-92)

The Department of Pediatrics at C.S. Mott Children's Hospital (the University of Michigan Medical Center) supports the bill. (4-6-92)

The Michigan Public Health Association wrote a letter in support of the bill dated May, 1991.