SUBJECT: Requiring additional newborn screening tests

COMMITTEE: Public Health — committee substitute recommended

VOTE: 6 ayes — Delisi, Laubenberg, Dawson, Jackson, McReynolds, Solis

0 nays

3 absent — Coleman, Truitt, Zedler

WITNESSES: For — Les Clow, Kimberly H. Countwright and Joseph W. Summers Institute of Metabolic Diseases; Charleta Guillory, March of Dimes; Laura Clow; Lillian Osowski; Melissa Skidmore; (*Registered, but did not testify:* Jennifer Banda, Texas Hospital Association; Jorey Berry and Sabrina Midkiff, March of Dimes; Erin Jones, Oz Systems; Lynda Woolbert, Coalition for Nurses in Advanced Practice)

Against — Clift Price, Texas Pediatric Society; Philip Vaughn, Pediatrix Screening; (*Registered, but did not testify:* Jaime Capelo, James Creswell, Todd Scharmberg, Pediatrix Medical Group; Kenneth Schaffer, Children's Cardiology Associates)

On — John Hellerstedt, Health and Human Services Commission; Jann Melton-Kissel and Susan Neill, Department of State Health Services; Brad Therrell, National Newborn Screening and Genetics Resource Center

BACKGROUND: Texas requires all newborns to be screened via heel prick for seven metabolic disorders:

- phenylketonuria (PKU), which involves an inability to process phenylalanine and, if left untreated, can cause mental retardation;
- galactosemia, a deficiency in one of the enzymes needed to metabolize sugar resulting in liver damage, mental retardation, growth failure, cataracts, or death, if untreated;
- congenital hypothyroidism, an inability to produce adequate amounts of thyroid hormone that can result in mental and physical retardation;

- three versions of sickle cell disease, an abnormality of red blood cells that can result in anemia, infection, gallstones, retinopathy, nephropathy, leg ulcers and myocardial dysfunction; and
- congenital adrenal hyperplasia (CAH), a deficiency of an adrenal enzyme that can cause chronic dehydration and inability to store energy as well as reproductive abnormalities in female infants.

The test is performed first within 24 to 48 hours of birth and a second time at the two-week check-up. Parents with a religious objection to the test may decline it. All newborns born in hospitals or large birthing centers also are screened for hearing loss.

The Department of State Health Services (DSHS) assembles the testing kits and sells them to private pay providers who are reimbursed by patients or insurers. Medicaid providers receive the kit at no charge, and DSHS is reimbursed by Medicaid. The collected specimens are processed by the DSHS newborn screening lab and the results conveyed to the practitioner. The tests for the seven metabolic disorders required by law are processed by the DSHS lab in Austin.

Children with one of the metabolic disorders or hearing loss may be eligible for the state-federal Children with Special Health Needs program, through which families may obtain financial assistance for health care services not available through private insurance, Medicaid, or CHIP.

DIGEST:

CSHB 790 would expand the required number of newborn screening tests to include a panel of conditions determined by DSHS, which could use the panel recommended by the American College of Medical Genetics or another appropriate report. The new panel would be required by November 1, 2006.

The bill would require DSHS to conduct a study to determine a cost-effective way to conduct newborn screening. One consideration would be the cost of DSHS labs processing the screening test or outsourcing it to a qualified lab with at least two years experience in newborn screening tests. DSHS would consult with a clinical geneticist, a family practitioner, a pediatrician, a hospital representative, and a parent of a child with a genetic disorder. DSHS periodically would review the cost-effectiveness of whichever option it chose and could adjust the amount it charged for newborn screening tests.

Children with one of the disorders screened by DSHS could be eligible for the state's Children with Special Health Care Needs program.

The bill would take effect September 1, 2005.

SUPPORTERS SAY:

Newborn screening for metabolic disorders is an inexpensive and easy public health service that identifies health problems that would not otherwise be apparent. Infants with these disorders usually seem fine when they are born, but fall ill when toxicity or a common infection overwhelms their systems. Although these disorders cannot be cured, their effects can be avoided with treatment or a change in diet. If parents knew their child had one of these disorders, they could avoid the serious health consequences, including mental retardation and death.

Texas' current panel of seven metabolic disorders is one of the least comprehensive of all states. Only eight other states require so few, and comparable states, including New York, Florida, and California, have moved toward more extensive screening.

Adding the new panel would not increase significantly the cost of newborn screening for parents, insurers, or the state. Under CSHB 790 DSHS could purchase or obtain the use of tandem mass spectrometry equipment, the lab equipment needed to process the expanded panel, or could outsource to a lab. The current panel is about $19.50 and includes seven disorders, while the expanded panel would add about $8.50 to the cost. Parents who purchase the expanded panel out of pocket today spend $25 in addition to the required $19.50 panel.

OPPONENTS SAY:

This bill would exacerbate a funding problem doctors have with the current law. Insurers do not always adequately reimburse for the service, often lumping it in with a global charge for well child services. Requiring additional tests would further erode the income doctors receive on infant visits.

OTHER OPPONENTS SAY:

This bill would not go far enough in helping parents whose children have metabolic disorders. Identifying a disorder is one step in the process, but Texas does not have an adequate referral network to ensure that children with disorders get the education and treatment they need. These are very specialized disorders, well beyond the usual practice of a family doctor, and the most appropriate course of action is referral to a geneticist and,

possibly, a nutritionist or other specialists. This problem is particularly prevalent along the border and in rural areas.

NOTES:

The committee substitute differs from the bill as filed in that it would permit DSHS to contract for the processing of the newborn screening tests if that were more cost-effective.

Both the House and Senate budget proposals include funding for the expanded panel.