SUBJECT: Newborn screening and the Newborn Screening Advisory Committee

COMMITTEE: Public Health — committee substitute recommended

VOTE: 9 ayes — Kolkhorst, Naishtat, J. Davis, Gonzales, Hopson, S. King, Laubenberg, Truitt, Zerwas

0 nays

2 absent — Coleman, McReynolds

WITNESSES: For — Aide Benson; Adrienne Kramer; Nicole Morris; William Morris; (*Registered, but did not testify:* Michael Benson; Erin Fellers; Antonio Gonzales; Mazie Jamison; Dustin Kramer; Larissa Moore; Stephen Moore; Jeannette Morris; William Morris; George Parks; Patricia Parks; Cecilia Perez; Eugenia Potthoff; Donald Smith, Texas Early Childhood Education Coalition)

Against — (*Registered, but did not testify:* Morgan Sanders, March of Dimes)

On — Susan Tanksley, Department of State Health Services

BACKGROUND: To the extent funding is available, the Department of State Health Services (DSHS) requires newborn screening tests for disorders listed in the core uniform panel of newborn screening conditions recommended in the 2005 American College of Medical Genetics report entitled "Newborn Screening: Toward a Uniform Screening Panel and System." The current screenings include all of the core uniform panel, except for cystic fibrosis screening. This testing detects 27 inherited diseases and hypothyroidism.

DIGEST: CSHB 1795 would establish "Greyson's Law" in memory of Greyson Morris. Greyson's Law would increase the number of screening tests conducted on newborns and would require DSHS to establish a Newborn Screening Advisory Committee.

DSHS would extend the list of required newborn screenings to include screenings for all core and secondary target conditions recommended in "Newborn Screening: Toward a Uniform Screening Panel and System," or

to be more stringent if determined necessary. DSHS could exclude from the required testing screening for galactose epimerase and galactokinase. DSHS also could require additional newborn screening tests based on the recommendations of the Newborn Screening Advisory Committee, which would be established by the bill.

The Newborn Screening Advisory Committee would be established by DSHS to advise the department about strategic planning, policy, rules, and services related to newborn screening and additional newborn screening tests. The advisory committee would include health care providers, a hospital representative, people with family members affected by conditions for which newborn screening could be conducted, and people involved in the delivery of newborn screening services, follow-up, or treatment. The advisory committee would have to meet at least three times each year and could appoint subcommittees.

The bill would take effect September 1, 2009. Newborns would not be required to be subjected to the additional screening tests until January 1, 2010.

SUPPORTERS SAY:

CSHB 1795 could enhance the treatment potential and quality of life for newborns who have one of the additional 24 disorders for which DSHS would screen. The conditions for which newborns are screened may have no immediate visible effects, but if not detected and treated early, could cause physical debilitation, cognitive disabilities, or death. This bill would be named in honor of Greyson Morris, an infant who passed away before his first birthday from Krabbe's disease, a genetic disorder detectable through newborn screenings.

One in 750 children is born with a genetic disorder detectable by newborn screening. However, Texas is among the bottom five states in the number of genetic conditions screened for in newborns. The American College of Medical Genetics, under commission by the U.S. Department of Health and Human Services, recommended that states screen newborns for 54 genetic diseases. The early detection of disorders included in the uniform panel can lead to interventions that could prevent children from crippling or deadly health issues. Many of the treatments for these disorders can be as simple as dietary changes.

The committee substitute would address concerns about the bill as filed in that cystic fibrosis would be included as it is one of the disorders in the

core screening panel. Texas is one of only a few states that do not screen for cystic fibrosis. Newborn screening for this disorder would reduce diagnostic costs for this condition in the future.

The core screening panel includes screening for the most severe form of galactosemia, a disorder that can lead to serious developmental problems and death. CSHB 1795 would allow DSHS to exclude screenings for two less-severe forms of galactosemia, galactose epimerase and galactokinase. These screenings are more costly than other tests, and they are included in the secondary targets list rather than the core panel because of their lesser severity. These forms of galactosemia do not cause death.

While some say additional screenings are too costly, this argument fails to weigh the value of saving a child's life and fails to account for the costs saved by families, insurers, and the Texas Medicaid program when early diagnosis and intervention leads to less costly long-term treatments. The Senate-passed version of the budget already includes funding for cystic fibrosis screening in Article 2, and the House-passed version of the budget includes, for consideration in Article 11, funding for screening cystic fibrosis and a contingency rider for funding the additional screenings in CSHB 1795.

OPPONENTS SAY:

CSHB 1795 would be too costly during difficult fiscal times. The state already screens for most of the disorders on the core panel recommended by the American College of Medical Genetics. Screening for the core panel is more critical than the secondary targets that would be added by this bill, because the core panel represents the disorders that are more severe, more prevalent, or more responsive to existing early interventions.

NOTES:

The introduced version of HB 1795 would have allowed DSHS to exclude cystic fibrosis from the newborn screening tests.

The fiscal note indicates CSHB 1795 would have a negative impact on general revenue funds of about $4.4 million in fiscal 2010-11. The bill would have higher costs of about $3.9 million in general revenue funds for implementation expenses in fiscal 2010 and would cost $495,401 in general revenue funds in subsequent fiscal years.

The House-passed version of SB 1 includes, for consideration in Article 11, a rider that would appropriate $4.1 million to conduct cystic fibrosis screenings and $4 million for a contingency rider for HB 1795. The

Senate-passed version of SB 1 includes funding in Article 2 for cystic fibrosis screening.

The companion bill, SB 1720 by Uresti, was reported favorably, as substituted, by the Senate Health and Human Services Committee on May 1 and recommended for the Local and Uncontested Calendar.