

SUBJECT: Requiring DSHS to provide information regarding Down syndrome

COMMITTEE: State Affairs — committee substitute recommended

VOTE: 7 ayes — Cook, Giddings, Farney, Geren, Huberty, Kuempel, Smithee

1 nay — Harless

4 absent — Craddick, Farrar, Oliveira, Sylvester Turner

WITNESSES: For — Suzanne Shepherd and Jeanette Holahan, Down Syndrome Association of Central Texas; Joe Pojman, Texas Alliance for Life; Katie McCann-Authement; Beverly Nuckols; Jenny Stone; (*Registered, but did not testify*: Chris Masey, Coalition of Texans with Disabilities; Kyleen Wright, Texans for Life; Ruth Allwein, Leah Brown, and Erin Groff, Texas Alliance for Life; Jeffrey Brooks, Texas Conservative Coalition; Gerard Jimenez, Texas Down Syndrome Advocacy Coalition; Emily Horne, Texas Right To Life; Jennifer Allmon, The Texas Catholic Conference of Bishops; John Davis; Vilma Luna)

Against — Carrie Kaufman, American Congress of Obstetrics and Gynecology, Texas Association of ObGYN, Texas Medical Association, TX Association of Family Physicians, Texas Pediatric Society, Texas Society of Genetic Counselors; Heather Busby, NARAL Pro-Choice Texas and the Trust Respect Access Coalition; Denee Booker; Heather Ross; (*Registered, but did not testify*: Rebecca Robertson, ACLU of Texas; Emily Rooke-Ley, Jane's Due Process; Amelia Long and Drew Stanley, NARAL Pro-Choice Texas; Ana DeFrates, National Latina Institute for Reproductive Health; Lucy Stein, Progress Texas; and 16 individuals)

DIGEST: CSHB 3374 would require the Department of State Health Services to make available information regarding Down syndrome that included:

- information addressing the overall development of individuals with Down syndrome;

- information about available treatment options for Down syndrome;
- contact information for national and local Down syndrome education and support programs, services, and organizations; and
- any other information required by the department.

This information would have to be current and evidence-based and published in English and Spanish. It would be available on the department's website in a format that could be easily printed. DSHS could provide this information in writing to health care providers if it was cost-effective.

A health care provider who tested for or initially diagnosed a child with Down syndrome would be required to provide the above information to:

- expectant parents who received a prenatal test result indicating a probability or diagnosis that the unborn child had Down syndrome;
- a parent of a child who received a test result suggesting a chance or diagnosis that the child had Down syndrome; or
- a parent of a child who received a diagnosis of Down syndrome.

In addition to providing the above information, a health care provider could provide additional, evidence-based information about Down syndrome.

A health care provider who was unable to access the above information would not be held civilly or criminally liable or subject to review or disciplinary action for failing to provide the information.

The bill would take effect September 1, 2015.

**SUPPORTERS  
SAY:**

CSHB 3374 would require that parents be educated on Down syndrome at the time they received this diagnosis. Many parents do not receive current, accurate information on Down syndrome or information about their local Down syndrome association at the time they receive a prenatal or postnatal diagnosis of Down syndrome. It would be beneficial for both children with Down syndrome and their parents if parents received this

information early. CSHB 3374 would not change options for parents but simply would help disseminate accurate and current information about Down syndrome. While this bill would establish a requirement for physicians, Down syndrome occurs in only about one of every several hundred births, so the bill would not be a large burden on physicians.

**OPPONENTS  
SAY:**

Parents should be presented with information and counseling on all available options upon receiving a prenatal diagnosis of Down syndrome, and the government should not attempt to sway decisions of parents who receive this diagnosis. Every family should receive evidence-based and unbiased information so they can make the right decision for them. CSHB 3374 inappropriately would require that physicians provide specific information to patients. Physicians are best trained and equipped to give patients accurate medical information and work with patients to determine when it is appropriate to receive such information and in what setting.