| SUBJECT:    | Transferring management of the Texas organ donation registry  |
|-------------|---|
| COMMITTEE:  | Public Health — committee substitute recommended  |
| VOTE:       | 11 ayes — Kolkhorst, Naishtat, Alvarado, Coleman, S. Davis, V. Gonzales, S. King, Laubenberg, Schwertner, Truitt, Zerwas  |
|             | 0 nays  |
| WITNESSES:  | For — Samuel Holtzman, LifeGift Organ Donation Center; ( <i>Registered</i> , <i>but did not testify</i> : David Marwitz, Texas Health Resources)  |
|             | Against — None  |
| BACKGROUND: | Health and Safety Code, sec. 692A.020 requires the Department of State<br>Health Services (DSHS) to partner with an association to promote,<br>manage, and maintain the Glenda Dawson Donate Life-Texas Registry, an<br>Internet-based statewide donor registry. DSHS is required to consult with<br>the Texas Organ, Tissue, and Eye Donor Council on educational materials,<br>employee training, and certain operational issues of the registry. |
| DIGEST:     | CSHB 2904 would require DSHS to contract with a nonprofit organization<br>to manage the Glenda Dawson Donate Life-Texas Registry by January 1,<br>2012. The nonprofit organization would have to include representatives<br>from each of the three organ procurement organizations in Texas.  |
|             | The bill would require the nonprofit organization to establish, maintain,<br>and manage a secure statewide Internet-based organ, tissue, and eye donor<br>registry that would allow donors to submit information directly and would<br>provide donor information to procurement organizations at any needed<br>time.  |
|             | The Department of Public Safety (DPS) would have to share educational materials about the registry developed by the nonprofit organization with driver's license and personal identification certificate applicants. DPS would transmit information on people who were interested in donating anatomical parts to the nonprofit organization electronically and at least monthly. DPS no longer would need to obtain written consent from           |

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potential organ donors to relay their information to this third party for inclusion in the registry.

Donations collected from DPS for the donor registry would be sent to the comptroller, who would disburse the money to the nonprofit organization. The nonprofit organization would have to submit to DSHS a written annual report showing how the money was used to manage the registry and produce and distribute educational materials.

The bill would prohibit the nonprofit organization, DPS, or any procurement organization from using or sharing information from the registry for profit. However, the nonprofit organization could accept donations and raise money for the purpose of registering donors.

The bill would abolish the Texas Organ, Tissue, and Eye Donor Council. The Glenda Dawson Donate Life-Texas Registry as it existed prior to January 1, 2012, also would be abolished. All property, money, contracts, leases, rights, and obligations would be transferred to DSHS. All information maintained by the registry before January 1, 2012, would be transferred to the nonprofit organization responsible for managing the registry after January 1, 2012.

The Texas Organ, Tissue, and Eye Donor Council would be abolished effective September 1, 2011, but the bill's other provisions would take effect January 1, 2012.

SUPPORTERS SAY: Since DSHS has many other responsibilities to fulfill, transferring management of the organ donor registry to a nonprofit organization represented by the state's three organ procurement organizations, as HB 2904 would require, would grow and manage the registry much more effectively. More than half of registries, including in populous states like California and Florida, use organ procurement organizations instead of state health departments to manage their organ donation registries. These states have experienced much more significant growth in the size of their registries with this type of management system. California's registry, for instance, is about eight times the size of Texas' registry, even though they began at about the same time.

In 2010, nearly 600 Texans died while waiting for a lifesaving organ transplant. With only 7 percent of Texans in the donation registry, Texas lags behind the rest of the country in terms of registered organ donors.

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|                   | Since 11,000 people in Texas currently are waiting for a transplant, maintaining a robust state registry is vital.  |
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|                   | Since only fees currently collected by the state could be transferred to the<br>nonprofit organization, and any additional cost would be borne by the<br>organization, the bill would not have any fiscal implication. With its<br>efficiencies, the bill likely would even save the state money.   |
| OPPONENTS<br>SAY: | Under the watch of DSHS, the organ donor registry has grown to over a million registrants since its inception only five years ago. Removing the registry from the state's control by privatizing it would force DSHS into overseeing and regulating its management from afar.   |
| NOTES:            | The committee substitute would ensure that volunteer donations collected<br>for the registry before January 1, 2012, could be used by DSHS in its<br>agreement with the nonprofit organization after that date. The committee<br>substitute also removed language requiring DPS to obtain written consent<br>before releasing information from potential organ donors. Among other<br>changes, the substitute would keep the name of the registry as the Glenda<br>Dawson Donate Life-Texas Registry. |