

- SUBJECT:** Establishing a consortium of Alzheimer's disease centers
- COMMITTEE:** Higher Education — favorable, without amendment
- VOTE:** 7 ayes — Rangel, Cuellar, F. Brown, Goolsby, J. Jones, Morrison, Wohlgemuth
- 0 nays
- 2 absent — Farabee, E. Reyna
- WITNESSES:** For — James W. Hinds, Texas Council on Alzheimer's Disease and Related Disorders; Kay Hricik, Alzheimer's Association Coalition of Texas; Esther Tangen, American Association of Retired Persons
- Against — None
- On — Thomas J. Fairchild, University of North Texas Health Science Center
- BACKGROUND:** Alzheimer's disease is a progressive, degenerative disease that attacks the brain and results in impaired memory, language, thinking, and behavior. It is the most common form of dementia — a severe loss of intellectual function that eventually leads to death. Alzheimer's is the fourth leading cause of death in adults, after heart disease, cancer and stroke.
- DIGEST:** HB 1504 would direct the Texas Council on Alzheimer's Disease and Related Disorders to establish a consortium of Alzheimer's disease centers. It initially would be composed of the Alzheimer's disease centers at Baylor College of Medicine, the Texas Tech University Health Sciences Center, and The University of Texas Southwestern Medical Center at Dallas. The council would provide funds to consortium members for clinical centers. The council would be able to add participants.
- The consortium would offer clinical services to all patients of the centers. It would establish a database to assist activities of each participating institution, encourage research projects, and provide information on patient health outcomes to Texas agencies and researchers. It would develop and distribute educational materials and services and would inform patients of research

projects open for their participation. The council would establish a data coordinating center located at one of the participating institutions and could restrict data access to consortium participants only.

HB 1504 would allow the council to receive state funding to establish and maintain the consortium and data coordinating center. The council could accept appropriations, as well as gifts, grants, and donations.

This bill would take immediate effect if finally passed by a two-thirds record vote of the membership of each house.

**SUPPORTERS
SAY:**

The consortium proposed by HB 1504 would provide a coordinated approach to taking care of Alzheimer's patients and making sure they have the best treatment and information regardless of where they live in Texas. It would increase the visibility of Texas research efforts, attracting more federal and private funds. It also would serve to attract the best doctors and researchers to Texas.

Alzheimer's usually affects one in ten people, beginning at 65 years of age. However, it can develop as early as age 40. By age 85, there is a 50 percent chance that anyone will contract the disease. Nearly 300,000 Texans have been diagnosed and that number is expected to double by the year 2010. There is no known cure. During the deterioration process, the average total cost for care is \$174,000, or \$12,000 to \$42,000 per year. These costs are partially absorbed by federal and state funds through Medicaid and Medicare.

The information gathered by the consortium proposed in HB 1504 could be used for planning and would help the council determine the needs of patients and their families. The database would help improve information on the demographics of Alzheimer's in Texas.

The process for disseminating information on new treatments and making people aware of new research would be improved. For example, a new study is attempting to prevent the development of the disease in certain at-risk people. With the database and data coordinating center proposed in HB 1504, potential patients could be identified quickly and offered the chance to participate.

Other large states, such as New York, California and Florida, have had consortiums in place for more than ten years. They have developed statewide networks with multiple sites that provide a uniform approach to the disease. They have contributed important research findings and are drawing in outside dollars.

OPPONENTS
SAY:

This bill would authorize an increase in state spending by \$1.2 million in the upcoming biennium. It would be better for Texas to direct this money to the participating institutions themselves. HB 1504 would create one more layer of bureaucracy within the state's health-related institutions of higher education. The bill would allow direct state appropriations to the consortium, which means this body could attach strings and conditions to the funding when it provides money to the participating institutions, rather than allowing them the freedom to use the money as they chose.

A consortium would duplicate what participating institutions would do if given the funding directly, without the costs of another institutional layer. The state ought to encourage its health-related institutions to share information and research about the disease among themselves, without setting up a state-mandated consortium.

OTHER
OPPONENTS
SAY:

In creating the consortium, the bill should include the University of North Texas Health Sciences Center at Fort Worth which already does work on Alzheimer's.

NOTES:

The House version of HB 1 by Junell, the general appropriations bill, has a provision in the Article 11 wish list to provide funding for this effort. Contingent upon enactment of House Bill 1504 or similar legislation, the Department of Health would receive \$615,000 in general revenue in fiscal 2000 and \$615,000 in fiscal 2001.