

**STORAGE NAME:** h2009.frc.doc  
**DATE:** March 11, 2002

**HOUSE OF REPRESENTATIVES**  
**FISCAL RESPONSIBILITY COUNCIL**  
**ANALYSIS**

**BILL #:** HB 2009 (PCB FRC 02-23)  
**RELATING TO:** Alzheimer's Disease Research  
**SPONSOR(S):** Fiscal Responsibility Council and Representative Byrd & others

**TIED BILL(S):**

**ORIGINATING COMMITTEE(S)/COUNCIL(S)/COMMITTEE(S) OF REFERENCE:**

- (1) FISCAL RESPONSIBILITY COUNCIL YEAS 23 NAYS 0
  - (2)
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**I. SUMMARY:**

THIS DOCUMENT IS NOT INTENDED TO BE USED FOR THE PURPOSE OF CONSTRUING STATUTES, OR TO BE CONSTRUED AS AFFECTING, DEFINING, LIMITING, CONTROLLING, SPECIFYING, CLARIFYING, OR MODIFYING ANY LEGISLATION OR STATUTE.

Alzheimer's disease (AD) is a progressive, irreversible brain disorder with no known cause or cure. Symptoms of the disease include memory loss, confusion, impaired judgment, personality changes, disorientation, and loss of language skills. Always fatal, Alzheimer's disease is the most common form of irreversible dementia. How rapidly it advances varies from person to person, but the brain disease eventually causes confusion, personality and behavior changes and impaired judgment. Communication becomes difficult as the affected person struggles to find words, finish thoughts or follow directions. Eventually, most people with Alzheimer's disease become unable to care for themselves.

Alzheimer's disease puts a heavy economic burden on society. A recent study estimated that the annual cost of caring for one Alzheimer's patient is \$18,408 for a patient with mild Alzheimer's, \$30,096 for a patient with moderate Alzheimer's disease, and \$36,132 for a patient with severe Alzheimer's disease. The annual national direct and indirect costs of caring for Alzheimer's patients are estimated to be as much as \$100 billion.

The bill establishes the Florida Alzheimer's Center and Research Institute at the University of South Florida and a not-for-profit corporation for the governance and operation of the center and Institute, pursuant to an agreement with the State Board of Education. The bill includes an appropriation of \$20 million towards the construction of a \$40 million research facility for the Institute and \$20 million for operating costs in FY 2002-2003, which includes funding for three contracts at \$5 million each with the Mayo Clinic in Jacksonville, the University of Florida, and the University of Miami to further the purposes of the act.

II. SUBSTANTIVE ANALYSIS:

A. DOES THE BILL SUPPORT THE FOLLOWING PRINCIPLES:

- |                                   |   |  |   |
|-----------------------------------|---|--|---|
| 1. <u>Less Government</u>         | Yes <input type="checkbox"/>            | No <input checked="" type="checkbox"/> | N/A <input type="checkbox"/>            |
| 2. <u>Lower Taxes</u>             | Yes <input type="checkbox"/>            | No <input type="checkbox"/>            | N/A <input checked="" type="checkbox"/> |
| 3. <u>Individual Freedom</u>      | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/>            | N/A <input type="checkbox"/>            |
| 4. <u>Personal Responsibility</u> | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/>            | N/A <input type="checkbox"/>            |
| 5. <u>Family Empowerment</u>      | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/>            | N/A <input type="checkbox"/>            |

For any principle that received a "no" above, please explain: The bill establishes a new institute on Alzheimer's research which promotes the ability of elderly Floridians and their families to maintain self-sufficiency.

B. PRESENT SITUATION:

Alzheimer's disease is a progressive, irreversible brain disorder with no known cause or cure. Symptoms of the disease include memory loss, confusion, impaired judgment, personality changes, disorientation, and loss of language skills. Always fatal, Alzheimer's disease is the most common form of irreversible dementia. How rapidly it advances varies from person to person, but it eventually causes confusion, personality and behavior changes and impaired judgment. Communication becomes difficult as the affected person struggles to find words, finish thoughts or follow directions. Most people with Alzheimer's disease become unable to care for themselves.

There is no known treatment that will cure Alzheimer's disease. For those who are currently suffering with the disease, medications can only help control symptoms and/or slow the progression of the disease. Approximately 100,000 victims die and 360,000 new cases of Alzheimer's disease are diagnosed each year in the United States. It is estimated that by 2050, 14 million Americans will have this disease. In every nation where life expectancy has increased, so has the incidence of Alzheimer's disease. Similarly, as Florida's population has aged, the incidents of Alzheimer's have risen. It is estimated that by 2020, 30 million people will be affected by this disorder worldwide and by 2050 the number could increase to 45 million.

Alzheimer's disease places an economic burden on society. A recent study estimated that the annual cost of caring for one Alzheimer's patient is \$18,408 for mild Alzheimer's disease, \$30,096 for moderate Alzheimer's disease, and \$36,132 for severe Alzheimer's disease (Leon et al., 1998). The annual national direct and indirect costs of caring for Alzheimer's patients are estimated to be as much as \$100 billion (Ernst and Hay, 1994; Ernst et al., 1997; Huang et al., 1988)<sup>1</sup>.

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<sup>1</sup>Ernst, R.L.; Hay, J.W. (1994). The U.S. Economic and Social Costs of Alzheimer's Disease Revisited. American Journal of Public Health, 84(8), 1261-1264. [PMID: 8059882](#)

Ernst, R.L.; Hay, J.W.; Fenn, C.; Tinklenberg, J.; Yesavage, J.A. (1997). Cognitive Function and the Costs of Alzheimer's Disease. An Exploratory Study. Archives of Neurology, 54(6), 687-693. [PMID: 9193203](#)

Huang, L.F.; Cartwright, W.S.; Hu, T.W. (1988). The Economic Cost of Senile Dementia in the United States, 1985. Public Health Reports, 103(1), 3-7. [PMID: 3124195](#)

The Florida Department of Elder Affairs has developed the Alzheimer's Disease Initiative (ADI) which provides services to address the special needs of individuals suffering from Alzheimer's disease and related memory disorders and their caregivers. Respite care (caregiver relief) services are provided in all 67 counties of the state. The program also provides funding for research into the cause, prevention, treatment and cure of Alzheimer's disease. Research is also done through the brain bank located at the Wien Center at Mt. Sinai Medical Center in Miami and the Mayo Clinic in Jacksonville, as well as several state universities.

The [National Institute on Aging](#) currently funds 29 Alzheimer's Disease Centers (ADC's) at major medical institutions across the nation. In addition, there are three Affiliate Centers. Researchers at these centers are working to translate research advances into improved care and diagnosis for Alzheimer's disease patients while, at the same time, focusing on the program's long-term goal-- finding a way to cure and possibly prevent AD. While Florida is second only to California in the number of individuals with Alzheimer's disease, Florida is host to only one of the affiliate centers (of the Mayo Clinic in Jacksonville).

<b>Alzheimer's Disease Centers</b>	<b>1990 Census Estimate of People with Alzheimer's Disease</b>
<u>California ---- (6 ADC's)</u>	469,759
<u>Florida</u>	<b>404,889</b>
<u>New York ---- (4 ADC's)</u>	339,441
<u>Pennsylvania ---- (2 ADC's)</u>	280,528
<u>Texas ---- (2 ADC's)</u>	265,861
<u>Illinois ---- (2 ADC's)</u>	219,357
<u>Ohio ---- (1 ADC)</u>	211,780
<u>Michigan ---- (1 ADC)</u>	166,429
<u>North Carolina ---- (1 ADC)</u>	127,952
<u>Massachusetts ---- (2 ADC's)</u>	120,546
<u>Missouri ---- (1 ADC)</u>	109,639
<u>Indiana ---- (1 ADC)</u>	106,047
<u>Georgia ---- (1 ADC)</u>	104,070
<u>Washington ---- (1 ADC)</u>	95,864
<u>Arizona --- (1 ADC)</u>	85,968
<u>Minnesota ---- (1 ADC)</u>	83,237
<u>Alabama ---- (1 ADC)</u>	80,983
<u>Maryland ---- (1 ADC)</u>	78,486
<u>Kentucky ---- (1 ADC)</u>	72,098
<u>Oregon ---- (1 ADC)</u>	65,738
<u>Arkansas --- (1 ADC)</u>	55,810

Alzheimer's research began to make significant progress with the 1990 discovery by a British research team of the first gene linked to the disorder. The next year, the University of South Florida hired the head and several other members of that team. Within a few years, the second gene linked to Alzheimer's disease was discovered at USF. Other research at USF has led to the discovery of links with brain blood vessels and brain inflammation and of links between Alzheimer's disease and

Down's syndrome. The development by USF of a strain of mice that carry two genes that cause Alzheimer's, and that develop symptoms quickly, has accelerated research into a vaccine.

In the 2000 Progress Report on Alzheimer's disease, the National Institute on Aging summarized the current state of research as follows:

*In the last 25 years, scientists have produced an extraordinary body of research findings on AD. Many of these findings have defined the genetic and biologic changes that underlie AD and offer possible targets for treatment. Researchers have identified drugs and other agents that could potentially counteract the pathologic changes that occur in AD and are testing many in clinical trials. They have made gains in defining people at high risk of developing AD. As methodologies are refined, scientists and clinicians will be able to investigate and understand the very earliest pathological and clinical signs of AD – perhaps 10 to 20 years before an actual clinical diagnosis is made<sup>2</sup>.*

A joint publication by the National Conference of State Legislatures and the Alzheimer's Association noted that ...

*The face of Alzheimer's disease is changing rapidly...Already, the first treatments have come to market, and researchers are optimistic that more effective treatments and preventions will be available within the decade.<sup>3</sup>*

#### C. EFFECT OF PROPOSED CHANGES:

The bill establishes the Florida Alzheimer's Center and Research Institute at the University of South Florida and a not-for-profit corporation for the governance and operation of the center and Institute, pursuant to an agreement with the State Board of Education. The corporation is to act as an instrumentality of the state. The not-for-profit corporation and any subsidiaries created by the corporation are authorized to receive, hold, invest, and administer property and any moneys received from private, state, and federal sources, as well as technical and professional income generated or derived from practice activities of the Institute, for the benefit of the Institute and the fulfillment of its mission.

The affairs of the corporation are to be managed by a board of directors who will serve without compensation. The President of the University of South Florida and the chair of the State Board of Education, or designee, are to be directors of the not-for-profit corporation, together with 5 representatives of the State University System and no more than 14 or fewer than 9 directors who are representatives of the public who are not medical doctors or state employees. Each director would have only one vote, serve a term of 3 years, and may be reelected to the board.

The initial board of directors would be composed of the President of the University of South Florida, the chair of the State Board of Education, 1 representative of the State University System and 3 representatives of the public who are not medical doctors or state employees appointed by the Governor, 2 representatives of the State University System and 3 representatives of the public who are not medical doctors or state employees appointed by the President of the Senate and 2 representatives of the State University System and 3 representatives of the public who are not

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<sup>2</sup> The National Institute on Aging (2000) 2000 Progress Report on Alzheimer's Disease, Alzheimer's Disease Education and Referral (ADEAR) Center, NIH Publication No. 00-4859.

<sup>3</sup> National Conference of State Legislatures, Alzheimer's Association. Alzheimer's Disease and Related Dementias: A Legislative Guide. Washington, D.C., March 2000.

medical doctors or state employees appointed by the Speaker of the House of Representatives. Subsequent directors would be elected by a majority vote of the board. The chair of the board of directors would be selected by majority vote of the directors.

The not-for-profit corporation would enter into an agreement with the State Board of Education that provides for utilization of university facilities, approval by the State Board of Education of articles of incorporation of the corporation and subsidiaries, a post audit of financial accounts, submission by the not-for-profit corporation of any other data relative to the operation of the not-for-profit corporation or a subsidiary, and EEO provisions. The State Board of Education is authorized to secure liability insurance for the not-for-profit corporation. The bill provides for the State Board of Education to assume governance and operation of the facilities in the event that agreement between the State Board of Education and the not-for-profit corporation is dissolved.

The bill provides for the board to appoint a chief executive officer of the Institute to serve at the pleasure of the board. The bill provides the chief executive officer with the authority to establish programs that fulfill the mission of the Institute in research, education, treatment, prevention, and early detection of Alzheimer's disease but requires approval by the State board of Education before any academic program is established that confers academic credit or awards degrees. The chief executive officer has control over the budget and funds appropriated or donated to the Institute. However, professional income generated by faculty from practice activities at the Institute would be shared between the Institute and the university as determined by the executive director and the appropriate university dean or vice president. The chief executive officer is authorized to appoint members of the Institute and set compensation, benefits and terms of service. Members of the Institute are eligible to hold concurrent appointments at affiliated academic institutions and university faculty are authorized to hold concurrent appointments at the Institute. The chief executive officer has control over the use and assignment of equipment and space within the Institute's facilities and may create the administrative structure necessary to carry out the mission of the Institute. The chief executive officer has a reporting relationship to the Commissioner of Education and is required to provide a copy of the Institute's annual report to the Governor and Cabinet, the President of the Senate, the Speaker of the House of Representatives, and the chair of the State Board of Education.

The bill also provides for the board of directors to establish a council of scientific advisors to review programs and recommend research priorities and initiatives to maximize the state's investment in the Institute. The State Board of Education would appoint five of the members of the council of scientific advisors.

The bill provides for an appropriation to construct facilities and operate the Institute (see the fiscal impact statement).

**D. SECTION-BY-SECTION ANALYSIS:**

See effect of proposed changes.

**III. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT:**

**A. FISCAL IMPACT ON STATE GOVERNMENT:**

**1. Revenues:**

It can be anticipated that the Institute will generate revenues by attracting research and educational grants and commercializing the products of research.

2. Expenditures:

The bill includes an appropriation of \$20 million from the Public Education Capital Outlay and Debt Service Trust Fund towards the construction of a \$40 million research facility for the Institute and \$20 million from the General Revenue Fund for operating costs in FY 2002-2003, which includes funding for three contracts at \$5 million each with the Mayo Clinic in Jacksonville, the University of Florida, and the University of Miami to further the purposes of the act. Finally, successful development of treatments for Alzheimer's disease and related complications by the Institute could result in reduced state expenditures.

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

N/A

2. Expenditures:

N/A

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

N/A

D. FISCAL COMMENTS:

N/A

IV. CONSEQUENCES OF ARTICLE VII, SECTION 18 OF THE FLORIDA CONSTITUTION:

A. APPLICABILITY OF THE MANDATES PROVISION:

N/A

B. REDUCTION OF REVENUE RAISING AUTHORITY:

N/A

C. REDUCTION OF STATE TAX SHARED WITH COUNTIES AND MUNICIPALITIES:

N/A

V. COMMENTS:

A. CONSTITUTIONAL ISSUES:

N/A

B. RULE-MAKING AUTHORITY:

N/A

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C. OTHER COMMENTS:

N/A

VI. AMENDMENTS OR COMMITTEE SUBSTITUTE CHANGES:

N/A

VII. SIGNATURES:

FISCAL RESPONSIBILITY COUNCIL:

Prepared by:

Staff Director:

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Robert Cox

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David K. Coburn