

HB 1449

2006
CS

CHAMBER ACTION

1 The Health Care General Committee recommends the following:

2
3 **Council/Committee Substitute**

4 Remove the entire bill and insert:

5 A bill to be entitled

6 An act relating to brain tumor research; creating s.
7 381.853, F.S.; providing legislative findings and intent;
8 requiring the Scripps Research Institute to work with the
9 University of Florida McKnight Brain Institute to develop
10 and maintain a brain tumor registry; providing that
11 individuals may choose not to be listed in the registry;
12 establishing the Florida Center for Brain Tumor Research
13 within the Scripps Research Institute; providing purpose
14 and goal of the center; requiring certain funds for brain
15 tumor research to be awarded on a competitive basis;
16 requiring the center to hold an annual brain tumor
17 biomedical technology summit; providing for clinical
18 trials and collaboration between certain entities;
19 requiring the center to submit an annual report to the
20 Governor, Legislature, and Secretary of Health; providing
21 for funding; establishing a scientific advisory council
22 and providing for composition and terms thereof; providing

HB 1449

2006
CS

23 rulemaking authority to the department; providing an
24 appropriation; providing an effective date.

25
26 Be It Enacted by the Legislature of the State of Florida:

27
28 Section 1. Section 381.853, Florida Statutes, is created
29 to read:

30 381.853 Florida Center for Brain Tumor Research.--

31 (1) The Legislature finds that each year an estimated
32 190,000 citizens of the United States are diagnosed with
33 cancerous and noncancerous brain tumors and that biomedical
34 research is the key to finding cures for these tumors. The
35 Legislature further finds that, although brain tumor research is
36 being conducted throughout the state, there is a lack of
37 coordinated efforts among researchers and health care providers.
38 Therefore, the Legislature finds that there is a significant
39 need for a coordinated effort to achieve the goal of curing
40 brain tumors. The Legislature further finds that the biomedical
41 technology sector meets the criteria of a high-impact sector,
42 pursuant to s. 288.108(6), having a high importance to the
43 state's economy with a significant potential for growth and
44 contribution to our universities and quality of life.

45 (2) It is the intent of the Legislature to establish a
46 coordinated effort among the state's public and private
47 universities and hospitals and the biomedical industry to
48 discover brain tumor cures and develop brain tumor treatment
49 modalities. Moreover, it is the intent of the Legislature to

HB 1449

2006
CS

50 expand the state's economy by attracting biomedical researchers
51 and research companies to the state.

52 (3) The Scripps Research Institute shall work with the
53 University of Florida McKnight Brain Institute to develop and
54 maintain a brain tumor registry that is an automated,
55 electronic, and centralized database of individuals with brain
56 tumors. The individual, or the parent or guardian of the
57 individual if the individual is a minor, may refuse to
58 participate in the brain tumor registry by signing a form
59 obtained from the Department of Health or from the health care
60 practitioner or entity that provides brain tumor care or
61 treatment, which indicates that the individual does not wish to
62 be included in the registry. The decision to not participate in
63 the registry must be noted in the registry.

64 (4) There is established within the Scripps Research
65 Institute the Florida Center for Brain Tumor Research.

66 (a) The purpose of the center is to provide a central
67 repository for brain tumor biopsies from individuals throughout
68 the state, improve and monitor brain tumor biomedical research
69 programs within the state, facilitate funding opportunities, and
70 foster improved technology transfer of brain tumor research
71 findings into clinical trials and widespread public use.

72 (b) The goal of the center is to find cures for brain
73 tumors.

74 (c) Funds specifically appropriated by the Legislature for
75 peer-reviewed brain tumor research shall be awarded on a
76 competitive basis by means of a grant process developed by the
77 center.

HB 1449

2006
CS

78 (d) The center shall hold an annual brain tumor biomedical
79 technology summit in the state to which scientists conducting
80 basic peer-reviewed scientific research from the state's public
81 and private universities, teaching hospitals, and for-profit and
82 nonprofit institutions are invited to share biomedical research
83 findings in order to expedite the discovery of cures. Summit
84 attendees shall cover the costs of such attendance or obtain
85 sponsorship for such attendance.

86 (e) The center shall encourage clinical trials in the
87 state on research that holds the promise of curing brain tumors.
88 The center shall facilitate partnerships between researchers,
89 physicians, clinicians, and hospitals for the purpose of sharing
90 new techniques and new research findings, as well as
91 coordinating the voluntary donation of brain tumor biopsies.

92 (f) The center shall facilitate the formation of
93 partnerships between researchers, physicians, clinicians, and
94 hospitals in the state.

95 (g) The center shall submit an annual report to the
96 Governor, the President of the Senate, the Speaker of the House
97 of Representatives, and the Secretary of Health no later than
98 January 15 that contains recommendations for legislative changes
99 necessary to foster a positive climate for the pursuit of brain
100 tumor research and the development of treatment modalities in
101 the state.

102 (h) The center shall be funded through private, state, and
103 federal sources.

104 (5) There is established within the center a scientific
105 advisory council that includes biomedical researchers,

HB 1449

2006
CS

106 physicians, clinicians, and representatives from public and
107 private universities and hospitals. The council shall meet at
108 least annually.

109 (a) The council shall consist of:

110 1. Two members from the University of Florida McKnight
111 Brain Institute, appointed by the Governor.

112 2. Two members from the Scripps Research Institute, one of
113 whom must have expertise in basic brain tumor research,
114 appointed by the Speaker of the House of Representatives.

115 3. Two members from other public and private state
116 universities and institutions directly involved in brain tumor
117 research, appointed by the President of the Senate.

118 4. Two physicians directly involved in the treatment of
119 brain tumor patients, appointed by the Secretary of Health.

120 (b) Council members shall serve staggered 4-year terms.

121 (c) Council members shall serve without compensation, and
122 each organization represented shall cover all expenses of its
123 representative.

124 (6) The Department of Health may adopt, repeal, and amend
125 rules pursuant to ss. 120.536(1) and 120.54 relating to the
126 center and the administration of the brain tumor registry. Such
127 rules may include procedures for participating in brain tumor
128 research and for providing access to confidential information
129 necessary for brain tumor investigations. For the purposes of
130 the brain tumor registry, the rules may include procedures for a
131 health care practitioner and researcher to obtain authorization
132 to use the brain tumor registry and methods for an individual or

HB 1449

2006
CS

133 | guardian to elect not to participate in the brain tumor
134 | registry.

135 | Section 2. The sum of \$4 million is appropriated from the
136 | General Revenue Fund to the Florida Center for Brain Tumor
137 | Research for the 2006-2007 fiscal year for the purpose of
138 | funding brain tumor research and funding for the procurement of
139 | brain tumor biopsies. From the total funds appropriated, an
140 | amount of up to 10 percent may be used for administrative costs.

141 | Section 3. This act shall take effect July 1, 2006.