

## CHAMBER ACTION

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1 The Health & Families Council recommends the following:

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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 Evelyn F. and William L. McKnight Brain  
9 Institute of the University of Florida to develop and  
10 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 Evelyn F. and William L. McKnight Brain  
14 Institute of the University of Florida; providing purpose  
15 and goal of the center; providing for a competitive grant  
16 process for awarding certain funds; requiring the center  
17 to hold an annual brain tumor biomedical technology  
18 summit; providing for clinical trials and collaboration  
19 between certain entities; requiring the center to submit  
20 an annual report to the Governor, Legislature, and  
21 Secretary of Health; providing for funding; establishing a  
22 scientific advisory council and providing for membership,

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23 terms of office, meetings, and compensation; 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

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

52 (3) The Evelyn F. and William L. McKnight Brain Institute  
53 of the University of Florida shall work with other institutions  
54 and organizations to develop and maintain a brain tumor registry  
55 that is an automated, electronic, and centralized database of  
56 individuals with brain tumors. The individual, or the parent or  
57 guardian of the individual if the individual is a minor, may  
58 refuse to participate in the brain tumor registry by signing a  
59 form obtained from the department 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) The Florida Center for Brain Tumor Research is  
65 established within the Evelyn F. and William L. McKnight Brain  
66 Institute of the University of Florida.

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

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

77 (c) Funds specifically appropriated by the Legislature for  
78 peer-reviewed brain tumor research shall be awarded using a  
79 competitive grant process developed by the center.

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

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

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

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

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

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

108 (a) The council shall consist of:

109 1. Two members from the Florida Center for Brain Tumor  
110 Research within the Evelyn F. and William L. McKnight Brain  
111 Institute of the University of Florida appointed by the  
112 Governor.

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

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

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

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

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

125 Section 2. The sum of \$500,000 is appropriated from the  
126 General Revenue Fund to the Evelyn F. and William L. McKnight  
127 Brain Institute of the University of Florida for the 2006-2007  
128 fiscal year. The level of funding for brain tumor research and  
129 the procurement of brain tumor biopsies shall be commensurate  
130 with the level of funding provided.

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