

1                                   A bill to be entitled  
 2           An act relating to brain tumor research; creating s.  
 3           381.853, F.S.; providing legislative findings and intent;  
 4           requiring the Department of Health to develop and maintain  
 5           a brain tumor registry; providing that individuals may  
 6           choose not to be listed in the registry; establishing the  
 7           Florida Center for Brain Tumor Research within the Scripps  
 8           Research Institute; providing purpose and goal of the  
 9           center; requiring the center to hold an annual brain tumor  
 10          biomedical technology summit; providing for clinical  
 11          trials and collaboration between certain entities;  
 12          providing for funding; establishing a scientific advisory  
 13          council and providing for composition and terms thereof;  
 14          providing rulemaking authority to the department;  
 15          providing an appropriation; providing an effective date.

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 17 Be It Enacted by the Legislature of the State of Florida:

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 19           Section 1.   Section 381.853, Florida Statutes, is created  
 20 to read:

21           381.853 Florida Center for Brain Tumor Research.--  
 22           (1) The Legislature finds that each year an estimated  
 23 190,000 citizens of the United States are diagnosed with  
 24 cancerous and noncancerous brain tumors and that biomedical  
 25 research is the key to finding cures for these tumors. The  
 26 Legislature further finds that, although brain tumor research is  
 27 being conducted throughout the state, there is a lack of  
 28 coordinated efforts among researchers and health care providers.

29 Therefore, the Legislature finds that there is a significant  
30 need for a coordinated effort to achieve the goal of curing  
31 brain tumors. The Legislature further finds that the biomedical  
32 technology sector meets the criteria of a high-impact sector,  
33 pursuant to s. 288.108(6), having a high importance to the  
34 state's economy with a significant potential for growth and  
35 contribution to our universities and quality of life.

36 (2) It is the intent of the Legislature to establish a  
37 coordinated effort among the state's public and private  
38 universities and hospitals and the biomedical industry to  
39 discover brain tumor cures and develop brain tumor treatment  
40 modalities. Moreover, it is the intent of the Legislature to  
41 expand the state's economy by attracting biomedical researchers  
42 and research companies to the state.

43 (3) The Department of Health shall develop and maintain a  
44 brain tumor registry that is an automated, electronic, and  
45 centralized database of individuals with brain tumors. The  
46 individual, or the parent or guardian of the individual if the  
47 individual is a minor, may refuse to participate in the brain  
48 tumor registry by signing a form obtained from the department or  
49 from the health care practitioner or entity that provides brain  
50 tumor care or treatment, which indicates that the individual  
51 does not wish to be included in the registry. The decision to  
52 not participate in the registry must be noted in the registry.

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

55 (a) The purpose of the center is to provide a central  
56 repository for brain tumor biopsies from individuals throughout

57 the state, improve and monitor brain tumor biomedical research  
58 programs within the state, facilitate funding opportunities, and  
59 foster improved technology transfer of brain tumor research  
60 findings into clinical trials and widespread public use.

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

63 (c) The center shall hold an annual brain tumor biomedical  
64 technology summit in the state to which physicians and  
65 biomedical researchers from the state's public and private  
66 universities and teaching hospitals are invited to share  
67 biomedical research findings in order to expedite the discovery  
68 of cures. Summit attendees shall cover the costs of such  
69 attendance or obtain sponsorship for such attendance.

70 (d) The center shall encourage clinical trials in the  
71 state on research that holds the promise of curing brain tumors.  
72 The center shall facilitate partnerships between researchers,  
73 treating physicians, and hospitals for the purpose of sharing  
74 new techniques and new research findings, as well as  
75 coordinating the voluntary donation of brain tumor biopsies.

76 (e) The center shall facilitate the formation of  
77 partnerships between researchers, physicians, and hospitals in  
78 the state.

79 (f) The center shall be funded through private, state, and  
80 federal sources.

81 (5) There is established within the center a scientific  
82 advisory council that includes biomedical researchers,  
83 physicians, and representatives from public and private

84 universities and hospitals. The council shall meet at least  
 85 annually.

86 (a) The council shall consist of representatives from:

- 87 1. The Scripps Research Institute.
- 88 2. A teaching hospital, as defined in s. 408.07.
- 89 3. Public and private state universities.
- 90 4. The Department of Health.
- 91 5. The Florida Medical Association.

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

93 (c) Members of the council shall serve without  
 94 compensation, and each organization represented shall cover all  
 95 expenses of its representative.

96 (6) The Department of Health may adopt, repeal, and amend  
 97 rules pursuant to ss. 120.536(1) and 120.54 relating to the  
 98 center and the administration of the brain tumor registry. Such  
 99 rules may include procedures for participating in brain tumor  
 100 research and for providing access to confidential information  
 101 necessary for brain tumor investigations. For the purposes of  
 102 the brain tumor registry, the rules may include procedures for a  
 103 health care practitioner and researcher to obtain authorization  
 104 to use the brain tumor registry and methods for an individual or  
 105 guardian to elect not to participate in the brain tumor  
 106 registry.

107 Section 2. The sum of \$4 million is appropriated from the  
 108 General Revenue Fund to the Florida Center for Brain Tumor  
 109 Research for the 2006-2007 fiscal year for the purpose of  
 110 funding brain tumor research and funding for the procurement of  
 111 brain tumor biopsies.

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