

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 Evelyn F. and William L. McKnight Brain
5 Institute of the University of Florida to develop and
6 maintain a brain tumor registry; providing that
7 individuals may choose not to be listed in the registry;
8 establishing the Florida Center for Brain Tumor Research
9 within the Evelyn F. and William L. McKnight Brain
10 Institute of the University of Florida; providing purpose
11 and goal of the center; providing for a competitive grant
12 process for awarding certain funds; requiring the center
13 to hold an annual brain tumor biomedical technology
14 summit; providing for clinical trials and collaboration
15 between certain entities; requiring the center to submit
16 an annual report to the Governor, Legislature, and
17 Secretary of Health; providing for funding; establishing a
18 scientific advisory council and providing for membership,
19 terms of office, meetings, and compensation; providing an
20 appropriation; providing an effective date.

21
22 Be It Enacted by the Legislature of the State of Florida:

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24 Section 1. Section 381.853, Florida Statutes, is created
25 to read:

26 381.853 Florida Center for Brain Tumor Research.--

27 (1) The Legislature finds that each year an estimated
28 190,000 citizens of the United States are diagnosed with
29 cancerous and noncancerous brain tumors and that biomedical
30 research is the key to finding cures for these tumors. The
31 Legislature further finds that, although brain tumor research is
32 being conducted throughout the state, there is a lack of
33 coordinated efforts among researchers and health care providers.
34 Therefore, the Legislature finds that there is a significant
35 need for a coordinated effort to achieve the goal of curing
36 brain tumors. The Legislature further finds that the biomedical
37 technology sector meets the criteria of a high-impact sector,
38 pursuant to s. 288.108(6), having a high importance to the
39 state's economy with a significant potential for growth and
40 contribution to our universities and quality of life.

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

48 (3) The Evelyn F. and William L. McKnight Brain Institute
49 of the University of Florida shall work with other institutions
50 and organizations to develop and maintain a brain tumor registry
51 that is an automated, electronic, and centralized database of
52 individuals with brain tumors. The individual, or the parent or
53 guardian of the individual if the individual is a minor, may

54 refuse to participate in the brain tumor registry by signing a
55 form obtained from the department or from the health care
56 practitioner or entity that provides brain tumor care or
57 treatment which indicates that the individual does not wish to
58 be included in the registry. The decision to not participate in
59 the registry must be noted in the registry.

60 (4) The Florida Center for Brain Tumor Research is
61 established within the Evelyn F. and William L. McKnight Brain
62 Institute of the University of Florida.

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

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

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

76 (d) The center shall hold an annual brain tumor biomedical
77 technology summit in the state to which scientists conducting
78 basic peer-reviewed scientific research from the state's public
79 and private universities, teaching hospitals, and for-profit and
80 nonprofit institutions are invited to share biomedical research

81 findings in order to expedite the discovery of cures. Summit
82 attendees shall cover the costs of such attendance or obtain
83 sponsorship for such attendance.

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

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

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

99 (5) There is established within the center a scientific
100 advisory council that includes biomedical researchers,
101 physicians, clinicians, and representatives from public and
102 private universities and hospitals. The council shall meet at
103 least annually.

104 (a) The council shall consist of:

105 1. Two members from the Florida Center for Brain Tumor
106 Research within the Evelyn F. and William L. McKnight Brain

107 Institute of the University of Florida appointed by the
108 Governor.

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

112 3. Two members from other public and private universities
113 and institutions directly involved in brain tumor research
114 appointed by the President of the Senate.

115 4. One member from the Mayo Clinic in Jacksonville who is
116 directly involved in the treatment of brain tumor patients or
117 who has expertise in basic brain tumor research appointed by the
118 Secretary of Health.

119 5. Two members from the Cleveland Clinic in Florida who
120 are directly involved in basic brain tumor research appointed by
121 the Governor.

122 6. One member from the H. Lee Moffitt Cancer Center and
123 Research Institute who is directly involved in the treatment of
124 brain tumor patients or who has expertise in basic brain tumor
125 research appointed by the Speaker of the House of
126 Representatives.

127 7. One member from the M. D. Anderson Cancer Center
128 Orlando who is directly involved in the treatment of brain tumor
129 patients or who has expertise in basic brain tumor research
130 appointed by the President of the Senate.

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

132 (c) Council members shall serve without compensation, and
133 each organization represented shall cover all expenses of its
134 representative.

135 Section 2. The sum of \$500,000 is appropriated from the
136 General Revenue Fund to the Evelyn F. and William L. McKnight
137 Brain Institute of the University of Florida for the 2006-2007
138 fiscal year. The level of funding for brain tumor research and
139 the procurement of brain tumor biopsies shall be commensurate
140 with the level of funding provided.

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