

By Senator Atwater

25-1215-06

See HB

1 A bill to be entitled

2 An act relating to brain tumor research;

3 creating s. 381.853, F.S.; providing

4 legislative findings and intent; requiring the

5 Department of Health to develop and maintain a

6 brain tumor registry; providing that

7 individuals may choose not to be listed in the

8 registry; establishing the Florida Center for

9 Brain Tumor Research within the Scripps

10 Research Institute; providing purpose and goal

11 of the center; requiring the center to hold an

12 annual brain tumor biomedical technology

13 summit; providing for clinical trials and

14 collaboration between certain entities;

15 providing for funding; establishing a

16 scientific advisory council and providing for

17 composition and terms thereof; providing

18 rulemaking authority to the department;

19 providing an appropriation; providing an

20 effective date.

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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

25 created 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

1 is being conducted throughout the state, there is a lack of
2 coordinated efforts among researchers and health care
3 providers. Therefore, the Legislature finds that there is a
4 significant need for a coordinated effort to achieve the goal
5 of curing brain tumors. The Legislature further finds that the
6 biomedical technology sector meets the criteria of a
7 high-impact sector, pursuant to s. 288.108(6), having a high
8 importance to the state's economy with a significant potential
9 for growth and contribution to our universities and quality of
10 life.

11 (2) It is the intent of the Legislature to establish a
12 coordinated effort among the state's public and private
13 universities and hospitals and the biomedical industry to
14 discover brain tumor cures and develop brain tumor treatment
15 modalities. Moreover, it is the intent of the Legislature to
16 expand the state's economy by attracting biomedical
17 researchers and research companies to the state.

18 (3) The Department of Health shall develop and
19 maintain a brain tumor registry that is an automated,
20 electronic, and centralized database of individuals with brain
21 tumors. The individual, or the parent or guardian of the
22 individual if the individual is a minor, may refuse to
23 participate in the brain tumor registry by signing a form
24 obtained from the department or from the health care
25 practitioner or entity that provides brain tumor care or
26 treatment, which indicates that the individual does not wish
27 to be included in the registry. The decision to not
28 participate in the registry must be noted in the registry.

29 (4) There is established within the Scripps Research
30 Institute the Florida Center for Brain Tumor Research.
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1 (a) The purpose of the center is to provide a central
2 repository for brain tumor biopsies from individuals
3 throughout the state, improve and monitor brain tumor
4 biomedical research programs within the state, facilitate
5 funding opportunities, and foster improved technology transfer
6 of brain tumor research findings into clinical trials and
7 widespread public use.

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

10 (c) The center shall hold an annual brain tumor
11 biomedical technology summit in the state to which physicians
12 and biomedical researchers from the state's public and private
13 universities and teaching hospitals are invited to share
14 biomedical research findings in order to expedite the
15 discovery of cures. Summit attendees shall cover the costs of
16 such attendance or obtain sponsorship for such attendance.

17 (d) The center shall encourage clinical trials in the
18 state on research that holds the promise of curing brain
19 tumors. The center shall facilitate partnerships between
20 researchers, treating physicians, and hospitals for the
21 purpose of sharing new techniques and new research findings,
22 as well as coordinating the voluntary donation of brain tumor
23 biopsies.

24 (e) The center shall facilitate the formation of
25 partnerships between researchers, physicians, and hospitals in
26 the state.

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

29 (5) There is established within the center a
30 scientific advisory council that includes biomedical
31 researchers, physicians, and representatives from public and

1 private universities and hospitals. The council shall meet at
2 least annually.

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

- 4 1. The Scripps Research Institute.
- 5 2. A teaching hospital, as defined in s. 408.07.
- 6 3. Public and private state universities.
- 7 4. The Department of Health.
- 8 5. The Florida Medical Association.

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

11 (c) Members of the council shall serve without
12 compensation, and each organization represented shall cover
13 all expenses of its representative.

14 (6) The Department of Health may adopt, repeal, and
15 amend rules pursuant to ss. 120.536(1) and 120.54 relating to
16 the center and the administration of the brain tumor registry.
17 Such rules may include procedures for participating in brain
18 tumor research and for providing access to confidential
19 information necessary for brain tumor investigations. For the
20 purposes of the brain tumor registry, the rules may include
21 procedures for a health care practitioner and researcher to
22 obtain authorization to use the brain tumor registry and
23 methods for an individual or guardian to elect not to
24 participate in the brain tumor registry.

25 Section 2. The sum of \$4 million is appropriated from
26 the General Revenue Fund to the Florida Center for Brain Tumor
27 Research for the 2006-2007 fiscal year for the purpose of
28 funding brain tumor research and funding for the procurement
29 of brain tumor biopsies.

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