

## House Bill No. 1449

An act relating to brain tumor research; creating s. 381.853, F.S.; providing legislative findings and intent; requiring the Evelyn F. and William L. McKnight Brain Institute of the University of Florida to develop and maintain a brain tumor registry; providing that individuals may choose not to be listed in the registry; establishing the Florida Center for Brain Tumor Research within the Evelyn F. and William L. McKnight Brain Institute of the University of Florida; providing purpose and goal of the center; providing for a competitive grant process for awarding certain funds; requiring the center to hold an annual brain tumor biomedical technology summit; providing for clinical trials and collaboration between certain entities; requiring the center to submit an annual report to the Governor, Legislature, and Secretary of Health; providing for funding; establishing a scientific advisory council and providing for membership, terms of office, meetings, and compensation; providing an effective date.

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

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

381.853 Florida Center for Brain Tumor Research.—

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

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

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

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

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

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

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

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

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

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

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

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

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

(a) The council shall consist of:

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

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

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

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

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

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

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

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

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

Section 2. This act shall take effect July 1, 2006.

Approved by the Governor June 20, 2006.

Filed in Office Secretary of State June 20, 2006.