

HOUSE OF REPRESENTATIVES STAFF ANALYSIS

BILL #: HB 1449 CS Brain Tumor Research
SPONSOR(S): Gannon and others
TIED BILLS: HB 1451 **IDEN./SIM. BILLS:** SB 2566

| REFERENCE | ACTION | ANALYST | STAFF DIRECTOR |
|---|-----------------|----------|----------------|
| 1) Health Care General Committee | 10 Y, 0 N, w/CS | Cicccone | Brown-Barrios |
| 2) Health Care Appropriations Committee | | | |
| 3) Health & Families Council | | | |
| 4) _____ | | | |
| 5) _____ | | | |

SUMMARY ANALYSIS

HB 1449 w/CS establishes the Florida Center for Brain Tumor Research within the Scripps Research Institute. The bill provides legislative intent regarding the need for coordination among researchers and health care providers in the effort to find cures for cancerous and noncancerous brain tumors.

This bill directs the Scripps Research Institute to work with the University of Florida McKnight Brain Institute to develop and maintain an automated centralized database of individuals with brain tumors. The bill creates the Florida Center for Brain Tumor Research within the Scripps Research Institute and directs the center to provide a central repository for brain tumor biopsies. In addition, the center is directed to improve and monitor brain tumor biomedical research programs, facilitate funding opportunities, and foster improved technology transfer of brain tumor research findings into clinical trials and public use.

The bill creates a scientific advisory council within the Florida Center for Brain Tumor Research includes biomedical researchers, physicians, clinicians, and representatives from public and private universities and hospitals. Members of the council serve without compensation.

The bill has a \$4 million fiscal impact. Funds would be appropriated from the General Revenue Fund to the Florida Center for Brain Tumor Research for the 2006-2007 fiscal year for the purpose of funding brain tumor research and the procurement of brain tumor biopsies. The bill provides that up to 10 percent of the total funds appropriated to be used for administrative costs.

The effective date of the bill is July 1, 2006.

FULL ANALYSIS

I. SUBSTANTIVE ANALYSIS

A. HOUSE PRINCIPLES ANALYSIS:

Provide limited government – The bill expands the duties and responsibilities of the Department of Health to develop and maintain an automated, electronic, and centralized brain tumor registry.

Empower families – Individuals in need of information and treatment of cancerous and noncancerous brain tumors would benefit from the advances in information and technology as biomedical research extends to expand clinical research trials and eventual cures.

B. EFFECT OF PROPOSED CHANGES:

Current sections of law delineate a growing emphasis to encourage biomedical and clinical trial research in a variety of tumor-related areas of study in Florida. Several universities, including the University of Florida, University of Miami and the University of South Florida have well established programs dealing with cancerous and noncancerous brain tumor research. In addition, the H. Lee Moffitt Cancer Center and Research Institute and the Florida Hospital in Orlando are listed in the national registry of brain tumor centers. Public and privately funded research consortiums such as the Scripps Research Institute provide a continuum of innovative research opportunities to foster communication and coordination among researchers and institutions, increase federal and other grant opportunities and expand the related economic industry growth.

Background

Tumors – General Definition

A tumor or neoplasm refers to a "new growth" of cells that already exist in a certain part of the body. Many different tumors can occur in the nervous system. They often cause headaches, seizures or neurological deficits. Tumors can be either benign or malignant. Malignant tumors are referred to as cancers. Tumor treatments can consist of surgical resection or biopsy, radiation approaches or drug treatment approaches (chemotherapy). Other tumors can be treated with modification of the body's own immune system (immunotherapy).¹

There are many types of brain tumor disorders including acoustic neuroma, astrocytoma, brain metastasis, and glioblastoma. Because of the many and varied types of brain tumors, treatment is complicated. Brain tumors in children are different from those in adults and are often treated differently. Although as many as 60% of children will survive, they are often left with long term side effects. In addition, brain tumors are the third leading cause of death in young adults ages 20-39.²

The American Cancer Society estimates that 18,820 Americans have been diagnosed with malignant brain or spinal cord tumors in 2005 and that 12,820 of these patients will die from these malignant tumors. 930 of these deaths that occurred in 2005 were in Florida.

The National Brain Tumor Foundation reports the following statistics:

- Each year approximately 190,000 people in the United States will be diagnosed with a primary or metastatic brain tumor.
- Brain tumors are the leading cause of Solid Tumor death in children under age 20 now surpassing acute lymphoblastic leukemia (ALL), and are the third leading cause of cancer death in young adults ages 20-39.

¹ See Department of Neurological Surgery, University of Pittsburg, www.neurosurgery.pitt.edu/conditions

² National Brain Tumor Foundation website www.braintumor.org/patient/treatment

- Brain tumor patients, including those with certain "benign" brain tumors, have poorer survival rates than breast cancer patients.
- Metastatic brain tumors (cancer that spreads from other parts of the body to the brain) occur at some point in 10 to 15% of persons with cancer and are the most common type of brain tumor. The incidence of brain tumors has been increasing as cancer patients live longer.
- In the United States, the overall incidence of all primary brain tumors is more than 14 per 100,000 people.
- Because brain tumors are located at the control center for thought, emotion and movement, their effects on an individual's physical and cognitive abilities can be devastating.
- Brain tumors are treated by surgery, radiation therapy and chemotherapy, used either individually or in combination.
- Only 31 percent of males and 30 percent of females survive five years following the diagnosis of a primary or malignant brain tumor.
- Brain tumors in children are different from those in adults and are often treated differently. Although as many as 69 percent of children with brain tumors will survive, they are often left with long-term side effects.
- Enhancing the quality of life of people with brain tumors requires access to quality specialty care, clinical trials, follow-up care and rehabilitative services. Improving the outlook for adults and children with brain tumors requires research into the causes of and better treatments of brain tumors.
- Complete and accurate data on all primary brain tumors are needed to provide the foundation for research leading to improved diagnosis and treatment and to investigations of its causes.

BRAIN TUMOR SYMPTOMS AND TREATMENT

Symptoms of a brain tumor can include headaches (of sufficient discomfort to disrupt sleep), seizures in a person who does not have a history of seizures, cognitive or personality changes, eye weakness, nausea or vomiting, speech disturbances, or memory loss. While these are the most common symptoms of a brain tumor, they can also indicate other medical problems.

At present, surgery is the primary treatment for brain tumors that lie within those membranes covering the brain or in parts of the brain that can be removed without damaging critical neurological functions. Because a tumor can regrow if any tumor cells are left behind, surgeons strive to remove the entire tumor whenever possible. Radiation therapy and chemotherapy, in general are used as secondary or adjuvant treatment for tumors that cannot be removed by surgery alone.

C. SECTION DIRECTORY:

Section 1. Creates s. 381.853, F.S., and provides legislative intent regarding cancerous and noncancerous biomedical research, directs the Scripps Research Institute to work with the University of Florida McKnight Brain Institute to develop and maintain a centralized database of brain tumor information, creates the Florida Center for Brain Tumor Research within the Scripps Research Institute, and creates a scientific advisory council.

Section 2. Provides a \$4 million appropriation from the General Revenue Fund to the Florida Center for Brain Tumor Research for the 2006-07 fiscal year.

Section 3. Provides an effective date of July 1, 2006.

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

None

2. Expenditures:

According to the Department of Health, the department will need additional funding to develop a specific automated, electronic and centralized database of individuals with brain tumors and to provide staffing necessary to maintain quality, completeness and timeliness of the registry data; develop and maintain rules; and to participate in the Advisory Council meetings and activities.

| <u>Estimated Expenditures</u> | 1 st Year | 2 nd Year (Annualized/Recurring) |
|---|----------------------|--|
| <u>Salaries</u> | | |
| 2 OMC II @\$38,048 | \$ 76,096 | \$ 77,997 |
| 1 OMC Mgr. @\$42,818 | \$ 42,818 | \$ 43,889 |
| 29% fringe | \$ 34,485 | \$ 35,347 |
| Total | <u>\$153,399</u> | <u>\$157,233</u> |
| <u>Expense</u> | | |
| 3 FTE @ Standard Professional Expense Package with Medium Travel \$16,460 1 st year - \$13,117 Recurring | \$ 49,380 | \$ 39,351 |
| Operating Capital Outlay | | |
| 3 FTE @ Standard OCO \$1,900 1 st year | \$ 5,700 | \$ - 0 - |
| Total Estimates Expenditures | <u>\$208,479</u> | <u>\$196,584</u> |

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

None

2. Expenditures:

None

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

None

D. FISCAL COMMENTS:

See Fiscal Note above.

III. COMMENTS

A. CONSTITUTIONAL ISSUES:

1. Applicability of Municipality/County Mandates Provision:

This bill does not require counties or municipalities to take an action requiring the expenditure of funds, nor does it reduce the authority that counties or municipalities have to raise revenue in the aggregate, nor does it reduce the percentage of state tax shared with counties or municipalities.

2. Other:

None

B. RULE-MAKING AUTHORITY:

The bill provides rule making authority for the Department of Health to implement the provisions of this bill.

C. DRAFTING ISSUES OR OTHER COMMENTS:

IV. AMENDMENTS/COMMITTEE SUBSTITUTE & COMBINED BILL CHANGES

On March 28, 2006, the House Health Care General Committee passed House Bill 1449 w/CS and adopted one strike-all amendment that made the following changes:

- Directed the Scripps Research Institute to work with the University of Florida McKnight Brain Institute to maintain a brain tumor registry.
- Established the Florida Center for Brain Tumor Research within the Scripps Research Institute.
- Provided for the brain tumor biomedical technology summit to include scientists conducting basic peer-reviewed scientific research.
- Clarified that the center shall include clinicians among researchers, physicians and hospitals fostering partnerships, information sharing and membership in the scientific advisory council.
- Provided annual reporting requirements.
- Specified up to 10 percent of the \$4 million appropriation to the Florida Center for Brain Tumor Research may be used for administrative costs.

The analysis is drafted to the bill as amended.