

STORAGE NAME: h0219s1.hcs

DATE: February 26, 1998

**HOUSE OF REPRESENTATIVES
COMMITTEE ON
HEALTH CARE SERVICES
BILL RESEARCH & ECONOMIC IMPACT STATEMENT**

BILL #: CS/HB 219

RELATING TO: Neurodegenerative Disorders

SPONSOR(S): Committee on Health Care Services, Rep. Greene & others

COMPANION BILL(S):

ORIGINATING COMMITTEE(S)/COMMITTEE(S) OF REFERENCE:

- (1) HEALTH CARE SERVICES YEAS 11 NAYS 0
 - (2) HEALTH & HUMAN SERVICES APPROPRIATIONS
 - (3)
 - (4)
 - (5)
-

SUMMARY:

This bill addresses issues dealing with neurodegenerative disorders including Alzheimer's disease and Parkinson's disease. Specifically, this bill:

- Limits membership to the Alzheimer's Disease Advisory Committee to two consecutive years;
- Creates the Parkinson's Disease Advisory Committee to advise the Department of Health and make recommendations to the Legislature regarding Parkinson's disease and similar neurodegenerative disorders and sets guidelines for performing its duties;
- Requires the committee to submit a preliminary report by December 1, 1999 and a final report by June 30, 2001;
- Specifies research and information to be included in the committee reports;
- Dissolves the Parkinson's Disease Advisory Committee on July 1, 2001;
- Specifies requirements for the membership of the Parkinson's Disease Advisory Committee;
- Creates and sets requirements for Parkinson's disease memory disorder clinics and day care and respite care programs;
- Provides an effective date of July 1, 1998 and dissolves the Committee on July 1, 2001.

Although no funding is provided in this bill, a source of revenue is necessary in order to implement the respite and daycare provisions in this bill. The degree to which these programs can be provided will be directly effected by the amount of funding appropriated to this bill. The Department of Elderly Affairs believes it will require an annual budget of \$378,238 to accomplish the provisions in this bill.

I. SUBSTANTIVE RESEARCH:

A. PRESENT SITUATION:

Parkinson's disease is a common progressive neurological disorder that results from degeneration of nerve cells in a region of the brain that controls movement. This degeneration creates a shortage of the brain signaling chemical known as dopamine, causing impaired movement. Drugs are often prescribed by doctors to help reduce the symptoms, and in patients who are severely affected, surgery known as pallidotomy is sometimes used. There is no cure for Parkinson's disease. The Florida Department of Health (DOH) estimates that Parkinson's disease costs society nearly 6 billion dollars every year.

Usually the first symptom of Parkinson's disease is tremor of a limb, which often begins on one side of the body. Other common symptoms include slow movement, an inability to move, rigid limbs, a shuffling gait, and a stooped posture. People with Parkinson's disease often show reduced facial expression, personality changes, dementia, sleep disturbances, speech impairments, or sexual difficulties.

In the United States, between 1 and 1.5 million people are believed to suffer from Parkinson's disease, and about 50,000 new cases are reported every year. Because the symptoms often appear later in life, the number of cases is expected to grow as the average age of the population increases over the next several decades. Forty percent of Americans with Parkinson's disease are under the age of 60.

There are many theories about the cause of Parkinson's disease. Until recently the prevailing theory was that one or more environmental factors caused the disease. Some researchers report families with inherited Parkinson's disease for more than a century.

In a recent collaborative study headed by the National Human Genome Research Institute (NHGRI) and the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health strong evidence was discovered of a gene on chromosome 4 that can lead to Parkinson's disease in some families. In June 1997 NHGRI research described how they found the gene and how a specific defect in it causes Parkinson's disease in these families. This gene may be responsible for a significant portion of a type of Parkinson's that appears in individuals before the age of 60. It is expected that information about this gene will help scientists gain further information about the causes of Parkinson's disease and perhaps aid in gaining information on other common and devastating brain disorders such as Alzheimer's disease.

The National Parkinson's Foundation in Miami, Florida provides the University of Miami each year with approximately \$500,000 in funds for Parkinson's disease research purposes. The foundation also funds approximately \$100,000 for Parkinson's disease research at the University of Florida. There are over 100 local unfunded support groups for patients with Parkinson's disease and their care givers to attend and exchange information.

The Department of Elder Affairs currently coordinates the Alzheimer's Disease Initiative, which is authorized by ss. 430.501-430.504, F.S. The program's purpose is to seek

innovative methods to meet the multi-stage, ever-changing needs of patients suffering from Alzheimer's disease and related memory disorders and their caregivers. The Alzheimer's Disease Initiative is a coordinated, comprehensive plan of care and is made up of five program components: Memory Disorder Clinics, which provide diagnostic and referral services for persons with memory problems, conduct research, and develop training material for caregivers; Model Alzheimer's Day Care programs, which provide specialized day care services designed for clients with a diminished level of functioning; Respite Care Programs, which provide a period of relief from a few hours a day to overnight, weekend or longer for the caregiver of an Alzheimer's client; The Alzheimer's Disease Research Brain Bank provides autopsies for Alzheimer's clients' brain tissues and matches clinical data with the pathological findings; and Alzheimer's Disease Advisory Committee, which is a ten member body that advises the Department of Elder Affairs on developments within the Alzheimer's Disease Initiative and on Alzheimer's related issues.

The Alzheimer's Disease Initiative provides case management to all Alzheimer's clients who are receiving respite or model day care services. Individuals are eligible for Alzheimer's Disease Initiative services who are diagnosed or suspected of having a memory loss where mental changes appear and gradually interfere with daily living activities. Caregivers of clients may receive training, and clients may be required to contribute an amount toward their services depending on their income.

The Department of Elder Affairs contracts directly with the Memory Disorder Clinics and the Alzheimer's Disease Brain Bank. The Department administers case management services and the Respite Care and Model Day Care programs through 11 area agencies on aging, which are public and private non-profit agencies responsible for the regional administration of a variety of elder care programs. These area agencies then contract with a variety of local service providers to provide the program's services.

B. EFFECT OF PROPOSED CHANGES:

A Parkinson's Disease Advisory Committee will be created to advise the Department of Elderly Affairs and the Department of Health and to make recommendations to the Legislature regarding Parkinson's disease and similar neurodegenerative disorders. The Committee shall submit a preliminary report by December 1, 1999 and a final report by June 30, 2001. The Committee will be dissolved on July 1, 2001. Alzheimer's disease memory disorder clinics and day care and respite care programs will be expanded to include Parkinson's disease clinics, daycare, and respite care programs. Membership to the Alzheimer's Disease Advisory Committee will be limited to two consecutive years.

C. APPLICATION OF PRINCIPLES:

1. Less Government:

a. Does the bill create, increase or reduce, either directly or indirectly:

(1) any authority to make rules or adjudicate disputes?

No.

(2) any new responsibilities, obligations or work for other governmental or private organizations or individuals?

Yes, the Department of Elderly Affairs will be required to supply staff support for the Parkinson's Disease Advisory Committee, and the Department of Elderly Affairs and the Department of Health will appoint members to the Committee.

(3) any entitlement to a government service or benefit?

No.

b. If an agency or program is eliminated or reduced:

(1) what responsibilities, costs and powers are passed on to another program, agency, level of government, or private entity?

N/A

(2) what is the cost of such responsibility at the new level/agency?

N/A

(3) how is the new agency accountable to the people governed?

N/A

2. Lower Taxes:

a. Does the bill increase anyone's taxes?

No.

b. Does the bill require or authorize an increase in any fees?

No.

c. Does the bill reduce total taxes, both rates and revenues?

No.

d. Does the bill reduce total fees, both rates and revenues?

No.

e. Does the bill authorize any fee or tax increase by any local government?

No.

3. Personal Responsibility:

a. Does the bill reduce or eliminate an entitlement to government services or subsidy?

No.

b. Do the beneficiaries of the legislation directly pay any portion of the cost of implementation and operation?

Yes, the department may assess patients receiving respite and daycare services with fees based on an overall ability to pay.

4. Individual Freedom:

a. Does the bill increase the allowable options of individuals or private organizations/associations to conduct their own affairs?

Yes, specialized respite and daycare programs will be created to provide services to persons with Parkinson's disease and similar neurodegenerative disorders and their families, and increased access to information may provide Parkinson's disease patients with improved medical treatment and additional options.

b. Does the bill prohibit, or create new government interference with, any presently lawful activity?

No.

5. Family Empowerment:

a. If the bill purports to provide services to families or children:

(1) Who evaluates the family's needs?

The family.

(2) Who makes the decisions?

The individual with the neurodegenerative disorder and/or the family.

(3) Are private alternatives permitted?

Yes.

(4) Are families required to participate in a program?

No.

(5) Are families penalized for not participating in a program?

No.

b. Does the bill directly affect the legal rights and obligations between family members?

No.

c. If the bill creates or changes a program providing services to families or children, in which of the following does the bill vest control of the program, either through direct participation or appointment authority:

(1) parents and guardians?

Yes.

(2) service providers?

No.

(3) government employees/agencies?

Yes.

D. STATUTE(S) AFFECTED:

Section 430.501, F.S. and s. 430.502, F.S.

E. SECTION-BY-SECTION RESEARCH:

Section 1. Limits membership to the Alzheimer's Disease Advisory Committee to two consecutive terms.

Section 2. Creates the Parkinson's Disease Advisory Committee, establishes requirements and guidelines, provides for membership selections, requires a preliminary and final report, and dissolves the committee on July 1, 2001.

Section 3. Creates and sets requirements for Alzheimer's and Parkinson's diseases memory disorder clinics and day care and respite care.

Section 4. Provides an effective date of July 1, 1998.

II. FISCAL RESEARCH & ECONOMIC IMPACT STATEMENT:

A. FISCAL IMPACT ON STATE AGENCIES/STATE FUNDS:

1. Non-recurring Effects:

| Department of Elderly Affairs | <u>1998-1999</u> | <u>1999-2000</u> | <u>2000-2001</u> |
|--|------------------|------------------|------------------|
| <u>Parkinson's Disease Advisory Committee:</u> | | | |
| Expense | \$10,000 | \$10,000 | \$10,000 |
| DOEA staff | \$68,000 | \$68,000 | \$68,000 |
| 1 FTE OMC II | | | |
| ½ OPS Staff Asst. | | | |
| TOTAL | \$78,000 | \$78,000 | \$78,000 |

2. Recurring Effects:

| Department of Elderly Affairs | <u>1998-1999</u> | <u>1999-2000</u> |
|--------------------------------------|---------------------|---------------------|
| <u>Respite and Daycare Programs:</u> | | |
| Staff salaries | \$107,279.51 | \$107,279.51 |
| Insurance | 5,262.00 | 5,262.00 |
| Transportation | 83,478.06 | 83,478.06 |
| Activities | \$ 7,504.00 | \$ 7,504.00 |
| TOTAL | \$203,523.00 | \$203,523.00 |
| Medicaid Waiver \$ for 8 clients | - 53,404.00 | - 53,404.00 |
| | \$150,119.00 | \$150,119.00 |

3. Long Run Effects Other Than Normal Growth:

See fiscal comments.

4. Total Revenues and Expenditures:

See fiscal comments.

B. FISCAL IMPACT ON LOCAL GOVERNMENTS AS A WHOLE:

1. Non-recurring Effects:

None.

2. Recurring Effects:

None.

3. Long Run Effects Other Than Normal Growth:

None.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

1. Direct Private Sector Costs:

None.

2. Direct Private Sector Benefits:

Respite and daycare programs provided through contracts with the Department of Elderly Affairs will provide patients with Parkinson's disease and other neurodegenerative disorders with an alternative to private respite and daycare services and may help to decrease costs for those patients and their families who otherwise might not have access to these services.

3. Effects on Competition, Private Enterprise and Employment Markets:

Respite and daycare programs provided through contracts with the Department of Elderly Affairs may increase the business of private respite and daycare programs.

D. FISCAL COMMENTS:

Funds to carry out the provisions of this bill are expected to be provided for in the Appropriations Committee. The extent of services the Department of Elderly Affairs can provide through public awareness and training programs, as well as contracting for respite and specialized daycare services, will be largely determined by the amount of revenue appropriated to this bill.

III. CONSEQUENCES OF ARTICLE VII, SECTION 18 OF THE FLORIDA CONSTITUTION:

A. APPLICABILITY OF THE MANDATES PROVISION:

This bill does not require counties or municipalities to spend funds or to take an action requiring the expenditure funds.

B. REDUCTION OF REVENUE RAISING AUTHORITY:

This bill does not reduce the authority that municipalities or counties have to raise revenues.

C. REDUCTION OF STATE TAX SHARED WITH COUNTIES AND MUNICIPALITIES:

This bill does not reduce the percentage of a state tax shared with counties or municipalities.

IV. COMMENTS:

None.

V. AMENDMENTS OR COMMITTEE SUBSTITUTE CHANGES:

The original provisions of HB 219 established a Department of Health/Agency for Health Care Administration Interagency Coordinating Committee on Parkinson's Disease to submit an annual report on Parkinson's disease and coordinate state health programs and activities relating to Parkinson's disease. The bill also provided for grants to support scientific research on Parkinson's disease and establish a statewide data system and an information clearinghouse to facilitate and enhance knowledge of Parkinson's disease.

On February 2, 1998, a strike everything amendment was approved by the Committee on Health Care Services. The amendment does the following:

- Limits membership to the Alzheimer's Disease Advisory Committee to two consecutive years;
- Creates the Parkinson's Disease Advisory Committee to advise the Department of Health and make recommendations to the Legislature regarding Parkinson's disease and similar neurodegenerative disorders and sets guidelines for performing its duties;
- Requires the committee to submit a preliminary report by December 1, 1999 and a final report by June 30, 2001;
- Specifies research and information to be included in the committee reports;
- Dissolves the Parkinson's Disease Advisory Committee on July 1, 2001;
- Specifies requirements for the membership of the Parkinson's Disease Advisory Committee;
- Creates and sets requirements for Alzheimer's and Parkinson's diseases memory disorder clinics and day care and respite care programs;
- Provides appropriations from the General Revenue Fund.

An amendment to the strike everything amendment was adopted to remove the provided appropriations.

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VI. SIGNATURES:

COMMITTEE ON HEALTH CARE SERVICES:

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