

By Representative Greene

1 A bill to be entitled
2 An act relating to Parkinson's disease;
3 creating the "Morris K. Udall Parkinson's
4 Research, Assistance, and Education Act of
5 1997"; providing purpose; providing for
6 establishment of programs; creating an
7 interagency coordinating committee; providing
8 duties of the committee; providing membership;
9 requiring an annual report; providing for
10 grants to research and training centers;
11 providing requirements; providing time
12 limitations; providing for review; providing
13 for data management and dissemination of
14 information; providing for grants to scientific
15 researchers; providing for a state education
16 program; providing an appropriation; providing
17 an effective date.

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19 WHEREAS, Parkinson's disease and related neurological
20 disorders affect as many as 1.5 million Americans, and

21 WHEREAS, approximately 40 percent of persons with
22 Parkinson's disease are under the age of 60, and

23 WHEREAS, research has found that in individuals with
24 Parkinson's disease, cells that produce a neurochemical called
25 dopamine inexplicably degenerate, causing uncontrollable
26 tremors, muscle stiffness, and loss of motor function, and

27 WHEREAS, Parkinson's disease causes disability and
28 suffering, renders individuals with the disease incapable of
29 caring for themselves, and places tremendous and prolonged
30 physical, emotional, and financial strain on the families and
31 loved ones of individuals with the disease, and

1 WHEREAS, it is estimated that the disease costs society
2 nearly \$6 billion annually, and

3 WHEREAS, only \$26 million annually is allocated
4 specifically for research on Parkinson's disease, or only
5 about \$1 for every \$200 in societal costs, and

6 WHEREAS, in order to find a cure or effective treatment
7 for Parkinson's disease, the investment in research must be
8 expanded and coordination among research institutions must be
9 strengthened, NOW, THEREFORE,

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

12
13 Section 1. Parkinson's disease; research, assistance,
14 and education.--

15 (1) SHORT TITLE.--This section may be cited as the
16 "Morris K. Udall Parkinson's Research, Assistance, and
17 Education Act of 1997."

18 (2) PURPOSE.--It is the purpose of this section to
19 provide for the expansion and coordination of research
20 concerning Parkinson's disease and to improve care and
21 assistance for individuals with the disease and their family
22 caregivers.

23 (3) ESTABLISHMENT OF PROGRAMS.--The Agency for Health
24 Care Administration, in conjunction with the Department of
25 Health, shall establish a program for the conduct and support
26 of research and training, and the dissemination of health
27 information, and may establish other programs, with respect to
28 Parkinson's disease.

29 (4) INTERAGENCY COORDINATING COMMITTEE.--The agency
30 and department shall establish a committee to be known as the
31 Interagency Coordinating Committee on Parkinson's Disease.

1 (a) The committee shall:
2 1. Provide for coordination of the activities of
3 research institutions in the state, with respect to
4 Parkinson's disease.
5 2. Coordinate state health programs and activities
6 relating to Parkinson's disease in order to assure the
7 adequacy, effectiveness, and technical soundness of these
8 programs and activities and to provide for the full
9 communication and exchange of information necessary to
10 maintain adequate coordination of the programs and activities.
11 3. Provide for coordination of state and federal
12 programs, research, assistance, and activities relating to
13 Parkinson's disease.
14 (b)1. The committee shall include: the Director of
15 Health Care Administration; the Secretary of Health;
16 representatives of divisions or agencies of the Departments of
17 Health, Children and Family Services, Elderly Affairs, and
18 Education whose programs involve health functions or
19 responsibilities relevant to Parkinson's disease; individuals
20 with Parkinson's disease and individuals with a family history
21 of Parkinson's disease; and health professionals or allied
22 health professionals.
23 2. The chair of the committee shall be the Director of
24 Health Care Administration.
25 3. The committee shall meet at the call of the chair,
26 but not less often than once each year.
27 (c) Not later than 120 days after the end of each
28 fiscal year, the committee shall prepare and submit a report
29 to the Governor, President of the Senate, and Speaker of the
30 House of Representatives detailing the activities of the
31 committee in carrying out its duties during that fiscal year.

1 (5) GRANTS TO RESEARCH AND TRAINING CENTERS.--
2 (a) The Director of Health Care Administration shall
3 award grants to encourage the development of innovative
4 multidisciplinary research and provide training concerning
5 Parkinson's disease. The director shall award not more than
6 10 grants and shall designate each center funded under such
7 grants as a Morris K. Udall Center for Research on Parkinson's
8 Disease.
9 (b) Each center assisted under this subsection shall:
10 1. Use the facilities of a single institution or a
11 consortium of cooperating institutions and shall meet such
12 qualifications as may be prescribed by the Director of Health
13 Care Administration.
14 2. Conduct basic and clinical research and provide
15 patient care services.
16 (c) Each center assisted under this subsection may:
17 1. Conduct training programs relating to Parkinson's
18 disease for scientists and health professionals.
19 2. Conduct programs to provide information and
20 continuing education, relating to Parkinson's disease, to
21 health professionals.
22 3. Conduct programs for the dissemination of
23 information relating to Parkinson's disease to the public.
24 4. Develop and maintain, where appropriate, a brain
25 bank to collect specimens related to the research and
26 treatment of Parkinson's disease.
27 (d) A center may use funds provided under paragraph
28 (a) to provide stipends for scientists and health
29 professionals enrolled in training programs under subparagraph
30 (c)1.
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1 (e) Support of a center under this subsection may be
2 for a period not exceeding 5 years. This period may be
3 extended by the Director of Health Care Administration for one
4 or more additional periods of not more than 5 years, if the
5 operations of such center have been reviewed by an appropriate
6 technical and scientific peer review group established by the
7 director, which has recommended that such period should be
8 extended.

9 (6) DATA MANAGEMENT; DISSEMINATION OF
10 INFORMATION.--The Department of Health shall:

11 (a) Establish a state Parkinson's Disease Data System
12 for the collection, storage, analysis, retrieval, and
13 dissemination of data derived from patient populations in the
14 state with Parkinson's disease, including, where possible,
15 data involving general populations for the purpose of
16 detection of individuals with a risk of developing the
17 disease.

18 (b) Establish a state Parkinson's Disease Information
19 Clearinghouse to facilitate and enhance knowledge and
20 understanding of the disease on the part of health
21 professionals, patients, and the public thorough the effective
22 dissemination of information.

23 (7) GRANTS TO SUPPORT SCIENTIFIC RESEARCHERS.--The
24 director shall establish a grant program to support scientists
25 who have distinguished themselves in the field of Parkinson's
26 disease research. Grants under this subsection shall be
27 utilized to enable established researchers to devote greater
28 time and resources in laboratories to conduct research on
29 Parkinson's disease and to encourage the development of a new
30 generation of researchers, with the support and guidance of
31 the most productive and innovative senior researchers.

1 (8) EDUCATION PROGRAM.--The Department of Health shall
2 establish a statewide education program designed to foster a
3 statewide focus on Parkinson's disease and the care of persons
4 with the disease. Activities under such program shall
5 include:

6 (a) Bringing together public and private organizations
7 to develop better ways to provide care to individuals with
8 Parkinson's disease and to assist the families of these
9 individuals.

10 (b) Providing technical assistance to public and
11 private organizations that offer support and aid to
12 individuals with Parkinson's disease and their families.

13 Section 2. There is hereby appropriated from the
14 General Revenue Fund to the Agency for Health Care
15 Administration and the Department of Health respective amounts
16 sufficient to carry out the provisions of this act for fiscal
17 year 1997-1998.

18 Section 3. This act shall take effect July 1, 1997.

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21 HOUSE SUMMARY

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23 Creates the "Morris K. Udall Parkinson's Research,
24 Assistance, and Education Act of 1997." Provides for
25 establishment and coordination of state programs for
26 research, training, assistance, and education relating to
27 Parkinson's disease. Provides for grants to research and
28 training centers and to scientific researchers. Provides
29 for data collection and management, dissemination of
30 information, and a statewide education program. Provides
31 duties of the Agency for Health Care Administration and
 the Department of Health in administering and
 coordinating programs under the act. Provides an
 appropriation.