

## HOUSE BILL No. 2041

By Representatives Dannebohm and Hawkins

1-16

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1 AN ACT enacting the Parkinson's disease public awareness and education  
2 act.

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4 *Be it enacted by the Legislature of the State of Kansas:*

5 Section 1. This act shall be known and may be cited as the  
6 "Parkinson's disease public awareness and education act."

7 Sec. 2. The Legislature finds and declares that:

8 (a) Parkinson's disease is a debilitating, painful and incurable  
9 neurological disorder of unknown origin that disrupts and can end the lives  
10 of those who suffer from it;

11 (b) Parkinson's disease causes diverse symptoms, including rigidity,  
12 slowness of movement, poor balance and tremors, which lead to an  
13 impaired ability to walk, speak, swallow and even breathe, so that the end  
14 result can be a clear mind trapped inside a body that has lost its ability to  
15 function;

16 (c) the visible symptoms of Parkinson's disease are often mistaken to  
17 be a normal part of the aging process;

18 (d) in addition, many people with the disease encounter precarious  
19 legal and personal situations in which they are erroneously thought to be  
20 under the influence of illegal or prescription drugs or alcohol due to their  
21 movement and gait patterns;

22 (e) Parkinson's disease takes an enormous emotional, psychological  
23 and physical toll on caregivers and families, potentially overwhelming  
24 their lives;

25 (f) it has been estimated that 1.5 million Americans have been  
26 diagnosed with Parkinson's disease, 50,000 more are diagnosed nationally  
27 each year and another 1.5 million persons have the disease but have never  
28 seen a neurologist;

29 (g) Parkinson's disease costs Americans \$25 billion per year,  
30 including medical treatments, disability payments and lost productivity;

31 (h) medications can only control some of the symptoms of the disease  
32 and only for uncertain periods of time;

33 (i) the "Morris K. Udall Parkinson's disease research act of 1997,"  
34 Pub. L. 105-78, provides federal funding through the national institutes of  
35 health for Parkinson's disease, and April 11 has been proclaimed to be  
36 world Parkinson's day in order to recognize the need for more research and

1 help in dealing with the devastating effects of this disease;

2 (j) increased public awareness and education are needed among  
3 health care, social services, judicial, law enforcement and emergency  
4 medical services personnel in order to better respond to the needs of  
5 Parkinson's disease patients and their caregivers and families; and

6 (k) it is imperative for Kansas to commit itself to actively support  
7 such public awareness and education efforts throughout the state in order  
8 to better meet the needs of its citizens who are suffering from Parkinson's  
9 disease.

10 Sec. 3. As used in this act:

11 (a) "Secretary" means the secretary of health and environment.

12 (b) "Department" means the department of health and environment.

13 (c) "Program" means the Parkinson's disease public awareness and  
14 education program established pursuant to this act.

15 Sec. 4. (a) The secretary of health and environment shall establish a  
16 Parkinson's disease public awareness and education program. The purpose  
17 of the program shall be to promote public awareness of Parkinson's disease  
18 and the value of early detection and possible treatments, including the  
19 benefits and risks of those treatments. The department of health and  
20 environment may accept, for that purpose, any special grant of moneys,  
21 services or property from the federal government or any of its agencies, or  
22 from any foundation, organization or medical school.

23 (b) The program shall include the following:

24 (1) Development of a public education and outreach campaign to  
25 promote Parkinson's disease awareness and education, including, but not  
26 limited to, the following subjects:

27 (A) The cause and nature of the disease;

28 (B) diagnostic procedures and appropriate indications for their use;

29 (C) lifestyle issues relating to how a person copes with Parkinson's  
30 disease, including, but not limited to, nutrition, diet and physical exercise;

31 (D) environmental safety and injury prevention; and

32 (E) availability of Parkinson's disease diagnostic and treatment  
33 services in the community;

34 (2) development of educational materials to be made available to  
35 consumers through local boards of health, physicians, hospitals and  
36 clinics;

37 (3) development of professional education programs for health care  
38 providers to assist them in understanding research findings and the  
39 subjects set forth in subsection (b)(1);

40 (4) development of educational programs for other personnel,  
41 including judicial staff, police officers, fire fighters and social services and  
42 emergency medical service providers, to assist them in recognizing the  
43 symptoms of Parkinson's disease and understanding how to respond to the

1 needs of persons with the disease in the course of performing their duties,  
2 including dissemination of the informational booklet prepared pursuant to  
3 section 5, and amendments thereto; and

4 (5) development and maintenance of a list of current providers of  
5 specialized services for the diagnosis and treatment of Parkinson's disease.  
6 Dissemination of the list shall be accompanied by a description of  
7 diagnostic procedures, appropriate indications for their use and a  
8 cautionary statement about the current status of Parkinson's disease  
9 research and treatment. The statement shall also indicate that the  
10 department does not endorse specific Parkinson's disease programs or  
11 centers in this state.

12 Sec. 5. (a) The department, in consultation with the Kansas chapters  
13 of the Parkinson's disease association, shall prepare an informational  
14 booklet in English and Spanish which provides, in a manner easily  
15 understandable by a patient or other non-healthcare professional,  
16 information about the symptoms and treatment of Parkinson's disease The  
17 booklet may contain any other information that the commissioner deems  
18 necessary and may be revised by the department whenever new  
19 information about Parkinson's disease becomes available.

20 (b) The department shall make a supply of the booklets available to  
21 all licensed health care facilities engaged in the diagnosis or treatment of  
22 Parkinson's disease and to those personnel described in section 4 (b)(4),  
23 and amendments thereto, as well as to health care professionals,  
24 community health centers and members of the public upon their request.  
25 The department shall publicize and make available the booklet to the  
26 maximum extent possible and shall make available electronically on its  
27 internet website in English and Spanish the information contained in the  
28 booklet.

29 Sec. 6. The secretary shall adopt rules and regulations to effectuate  
30 the purposes of this act.

31 Sec. 7. This act shall take effect and be in force from and after its  
32 publication in the statute book.