1 AN ACT concerning health.

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

- Section 1. Short title. This Act may be cited as the Parkinson's Disease Public Awareness and Education Act.
- 6 Section 5. Findings. The General Assembly finds the 7 following:
 - (1) Parkinson's disease is a debilitating, painful, and incurable neurological disorder of unknown origin that disrupts and can end the lives of those who suffer from it.
 - (2) Parkinson's disease causes diverse symptoms, including rigidity, slowness of movement, poor balance, and tremors, which lead to an impaired ability to walk, speak, swallow, and even breathe, so that the end result can be a clear mind trapped inside a body that has lost its ability to function.
 - (3) The visible symptoms of Parkinson's disease are often mistaken to be a normal part of the aging process.
 - (4) In addition, many people with the disease encounter precarious legal and personal situations in which they are erroneously thought to be under the influence of illegal or prescription drugs or alcohol due to their movement and gait patterns.

- (5) Parkinson's disease takes an enormous emotional, psychological, and physical toll on caregivers and families, potentially overwhelming their lives.
 - (6) It has been estimated that 1,500,000 Americans have been diagnosed with Parkinson's disease, 50,000 more are diagnosed nationally each year, and another 1,500,000 persons have the disease but have never seen a neurologist.
 - (7) Parkinson's disease costs Americans \$25,000,000,000 per year, including medical treatments, disability payments, and lost productivity.
 - (8) Medications can only control some of the symptoms of the disease and only for uncertain periods of time.
 - (9) The federal Morris K. Udall Parkinson's Disease Research Act of 1997 provides federal funding through the National Institutes of Health for Parkinson's disease, and April 11 has been proclaimed to be World Parkinson's Day in order to recognize the need for more research and help in dealing with the devastating effects of this disease.
 - (10) Increased public awareness and education are needed among health care, social services, judicial, law enforcement, and emergency medical services personnel in order to better respond to the needs of Parkinson's disease patients and their caregivers and families.
 - (11) It is imperative for Illinois to commit itself to actively support such public awareness and education efforts throughout the State in order to better meet the

- 1 needs of its citizens who are suffering from Parkinson's
- disease.
- 3 Section 10. Definitions. In this Act:
- 4 "Department" means the Department of Public Health.
- 5 "Director" means the Director of Public Health.
- 6 "Program" means the Parkinson's Disease Public Awareness
- 7 and Education Program established under this Act.
- 8 Section 15. Parkinson's Disease Public Awareness and
- 9 Education Program.
- 10 (a) Subject to appropriation, the Director shall establish
- 11 a Parkinson's Disease Public Awareness and Education Program.
- 12 (b) The purpose of the Program is to promote public
- 13 awareness of Parkinson's disease and the value of early
- 14 detection and possible treatments, including the benefits and
- 15 risks of those treatments. The Department may accept for that
- purpose any special grant of moneys, services, or property from
- 17 the federal government or any of its agencies, or from any
- 18 foundation, organization, or medical school.
- 19 (c) The Program shall include the following:
- 20 (1) Development of a public education and outreach
- campaign to promote Parkinson's disease awareness and
- 22 education, including, but not limited to, the following
- 23 subjects:
- 24 (A) the cause and nature of the disease;

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this Act.

- 1 (B) diagnostic procedures appropriate and 2 indications for their use; (C) lifestyle issues relating to how a person copes 3 with Parkinson's disease, including, but not limited to, nutrition, diet, and physical exercise; (D) environmental safety and injury prevention; 6 7 and 8 (E) availability of Parkinson's disease diagnostic 9 and treatment services in the community. 10 (2) Development of educational materials to be made 11 available to consumers through local physicians, 12 hospitals, clinics, and boards of health. 13 (3) Development of professional education programs for 14 health care providers to assist them in understanding 15 research findings and the subjects set forth in paragraph 16 (1) of this subsection. 17 (4) Development of educational programs for other personnel, including judicial staff, police officers, fire 18 19 fighters, and social services and emergency medical 20 service providers, to assist them in recognizing the symptoms of Parkinson's disease and understanding how to 21 22 respond to the needs of persons with the disease in the
 - (5) Development and maintenance of a list of current

course of performing their duties, including dissemination

of the informational booklet prepared under Section 20 of

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providers of specialized services for the diagnosis and treatment of Parkinson's disease. Dissemination of the list shall be accompanied by a description of diagnostic procedures, appropriate indications for their use, and a cautionary statement about the current status of Parkinson's disease research and treatment. The statement shall also indicate that the Department does not endorse specific Parkinson's disease programs or centers in this State.

Section 20. Informational booklet.

- (a) The Department, in consultation with the Midwest Chapter of the American Parkinson Disease Association, any public or private university medical school that the Director deems useful, including, but not limited to, Loyola Medical School, and the Department on Aging, shall prepare an informational booklet in English, Spanish, and Mandarin that provides, in a manner easily understandable by a patient or other non-health care professional, information about the symptoms and treatment of Parkinson's disease. The booklet may contain any other information that the Department deems necessary and may be revised by the Department whenever new information about Parkinson's disease becomes available.
- (b) The Department shall make a supply of the booklets available to all licensed health care facilities engaged in the diagnosis or treatment of Parkinson's disease and to those

- personnel described in paragraph (4) of subsection (c) of Section 15 of this Act, as well as to health care professionals, community health centers, and members of the public upon their request. The Department shall publicize and make available the booklet to the maximum extent possible, and shall make available electronically on its website in English and Spanish the information contained in the booklet.
- 8 Section 25. Rules. The Director shall adopt rules to 9 effectuate the purposes of this Act.