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THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE BILL

No. 702 Session of 2005

INTRODUCED BY WATSON, BASTIAN, GINGRICH, PISTELLA, PICKETT, BALDWIN, BROWNE, CALTAGIRONE, CAPPELLI, CLYMER, DALEY, FABRIZIO, GEORGE, GOODMAN, HENNESSEY, JAMES, KIRKLAND, LEACH, MAHER, S. MILLER, O'NEILL, RUBLEY, E. Z. TAYLOR, THOMAS, TIGUE AND YOUNGBLOOD, MARCH 1, 2005

REFERRED TO COMMITTEE ON HEALTH AND HUMAN SERVICES, MARCH 1, 2005

AN ACT

Establishing standards of care for Huntington's disease patients; and providing for the powers and duties of the Department of Health.

The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows:

Section 1. Short title.

This act shall be known and may be cited as the Huntington's Disease Quality of Care Act.

Section 2. Legislative findings.

The General Assembly finds and declares as follows:

(1) About 30,000 people have Huntington's disease in the United States; estimates of its prevalence are about one in every 10,000 persons. At least 150,000 others have a 50% risk of developing the disease, and thousands more of their relatives live with the possibility that they, too, might develop Huntington's disease.

(2) Huntington's disease results from genetically programmed degeneration of nerve cells, called neurons, in certain areas of the brain. This degeneration causes uncontrolled movements, loss of intellectual faculties and emotional disturbance. The disease affects structures within the brain which coordinate movement, thought, perception and memory. It is a pervasive disease.

(3) Huntington's disease is found in every country of the world. It is a familial disease that is passed from parent to child through a genetic mutation.

(4) Individuals with Huntington's disease face progressive deterioration of their physical, emotional and behavioral functions. Symptoms include chorea, or severe involuntary movements of the extremities, unsteady gait, inarticulate speech, dysphagia which places them at risk for aspiration and pneumonia, cognitive loss and behavioral problems. The management and care of this disease require a skilled interdisciplinary team of workers, including nurses, physicians, rehabilitation and recreational specialists, nutritionists and social workers. Pharmacy, dentistry, neurological and psychiatric services should also be readily available to those individuals who suffer from this disease.

(5) There is no cure for Huntington's disease, but current medications enable a much better quality of life for those with Huntington's. Most drugs used to treat the symptoms of Huntington's disease have side effects such as fatigue, restlessness or hyperexcitability. While medicines may help keep these clinical symptoms under control, there is no treatment to stop or reverse the course of the disease.

(6) The lack of additional reimbursement creates

disincentives for many nursing homes to provide specialized services to care for individuals with Huntington's disease. The limited options for residential care are compounded by several interrelated factors:

(i) Huntington's disease patients tend to age in place. Their long lengths of stay reduce placement opportunities for other affected individuals.

(ii) Due to the progressive course of their disease, the care needs of Huntington's patients become more complex and costly.

(iii) Due to the complex and intensive medical, nursing, rehabilitative and psychological care needs of this population, Huntington's disease is best treated in discrete units by an interdisciplinary team as opposed to scattered beds, a costly option for most nursing homes.

(iv) Their care needs are more expensive as compared with the traditional geriatric nursing home resident.

Section 3. Duties of Department of Health.

(a) Regulations.--The Department of Health shall promulgate regulations to ensure the quality of care for Huntington's disease patients in all care settings licensed by the department as soon as practicable to implement this act. The regulations shall be as consistent as possible with applicable Federal regulations and the legislative findings of the General Assembly.

(b) Administrative fees.--The department shall assess the reasonableness of administrative fees on all care settings licensed by the department to cover the costs of applicable administrative actions.

Section 4. Effective date.

This act shall take effect in 60 days.