

AN ACT concerning State government.

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

Section 5. The Department of Public Health Powers and Duties Law of the Civil Administrative Code of Illinois is amended by adding Section 2310-665 as follows:

(20 ILCS 2310/2310-665 new)

Sec. 2310-665. Multiple Sclerosis Task Force.

(a) The General Assembly finds and declares the following:

(1) Multiple sclerosis (MS) is a chronic, often disabling, disease that attacks the central nervous system, which is comprised of the brain, spinal cord, and optic nerves. MS is the number one disabling disease among young adults, striking in the prime of life. It is a disease in which the body, through its immune system, launches a defensive and damaging attack against its own tissues. MS damages the nerve-insulating myelin sheath that surrounds and protects the brain. The damage to the myelin sheath slows down or blocks messages between the brain and the body.

(2) Most people experience their first symptoms of MS between the ages of 20 and 40, but MS can appear in young children and teens as well as much older adults. MS

symptoms can include visual disturbances, muscle weakness, trouble with coordination and balance, sensations such as numbness, prickling or pins and needles, and thought and memory problems. MS patients can also experience partial or complete paralysis, speech impediments, tremors, dizziness, stiffness and spasms, fatigue, paresthesias, pain, and loss of sensation.

(3) The cause of MS remains unknown; however, having a first-degree relative, such as a parent or sibling, with MS significantly increases a person's risk of developing the disease. According to the National Institute of Neurological Disorders and Stroke, it is estimated that there are approximately 250,000 to 350,000 persons in the United States who are diagnosed with MS. This estimate suggests that approximately 200 new cases are diagnosed each week. Other sources report a population of at least 400,000 in the United States. The estimate of persons with MS in Illinois is 20,000, with at least 2 areas of MS clusters identified in Illinois.

(4) Presently, there is no cure for MS. The complex and variable nature of the disease makes it very difficult to diagnose, treat, and research. The cost to the family, often with young children, can be overwhelming. Among common diagnoses, non-stroke neurologic illnesses, such as multiple sclerosis, were associated with the highest out-of-pocket expenditures (a mean of \$34,167), followed

by diabetes (\$26,971), injuries (\$25,096), stroke (\$23,380), mental illnesses (\$23,178), and heart disease (\$21,955). Median out-of-pocket costs for health care among people with MS, excluding insurance premiums, were almost twice as much as the general population. The costs associated with MS increase with greater disability. Costs for severely disabled individuals are more than twice those for persons with a relatively mild form of the disease. A recent study of medical bankruptcy found that 62.1% of all personal bankruptcies in the United States were related to medical costs.

(5) Therefore, it is in the public interest for the State to establish a Multiple Sclerosis Task Force in order to identify and address the unmet needs of persons with MS and develop ways to enhance their quality of life.

(b) There is established the Multiple Sclerosis Task Force in the Department of Public Health. The purpose of the Task Force shall be to:

(1) develop strategies to identify and address the unmet needs of persons with MS in order to enhance the quality of life of persons with MS by maximizing productivity and independence and addressing emotional, social, financial, and vocational challenges of persons with MS;

(2) develop strategies to provide persons with MS greater access to various treatments and other therapeutic

options that may be available; and

(3) develop strategies to improve multiple sclerosis education and awareness.

(c) The Task Force shall consist of 16 members as follows:

(1) the Director of Public Health and the Director of Human Services, or their designees, who shall serve ex officio; and

(2) fourteen public members, who shall be appointed by the Director of Public Health as follows: 2 neurologists licensed to practice medicine in this State; 3 registered nurses or other health professionals with MS certification and extensive expertise with progressed MS; one person upon the recommendation of the National Multiple Sclerosis Society; 3 persons who represent agencies that provide services or support to individuals with MS in this State; 3 persons who have MS, at least one of whom having progressed MS; and 2 members of the public with a demonstrated expertise in issues relating to the work of the Task Force.

Vacancies in the membership of the Task Force shall be filled in the same manner provided for in the original appointments.

(d) The Task Force shall organize within 120 days following the appointment of a majority of its members and shall select a chairperson and vice-chairperson from among the members. The chairperson shall appoint a secretary who need not be a member of the Task Force.

(e) The public members shall serve without compensation and shall not be reimbursed for necessary expenses incurred in the performance of their duties unless funds become available to the Task Force.

(f) The Task Force may meet and hold hearings as it deems appropriate.

(g) The Department of Public Health shall provide staff support to the Task Force.

(h) The Task Force shall report its findings and recommendations to the Governor and to the General Assembly, along with any legislative bills that it desires to recommend for adoption by the General Assembly, no later than December 31, 2015.

(i) The Task Force is abolished and this Section is repealed on January 1, 2016.

Section 99. Effective date. This Act takes effect upon becoming law.