

1 AN ACT concerning State government.

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

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

7 (20 ILCS 2310/2310-665 new)

8 Sec. 2310-665. Multiple Sclerosis Task Force.

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

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

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

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

8 (3) The cause of MS remains unknown; however, having a
9 first-degree relative, such as a parent or sibling, with MS
10 significantly increases a person's risk of developing the
11 disease. According to the National Institute of
12 Neurological Disorders and Stroke, it is estimated that
13 there are approximately 250,000 to 350,000 persons in the
14 United States who are diagnosed with MS. This estimate
15 suggests that approximately 200 new cases are diagnosed
16 each week. Other sources report a population of at least
17 400,000 in the United States. The estimate of persons with
18 MS in Illinois is 20,000, with at least 2 areas of MS
19 clusters identified in Illinois.

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

1 by diabetes (\$26,971), injuries (\$25,096), stroke
2 (\$23,380), mental illnesses (\$23,178), and heart disease
3 (\$21,955). Median out-of-pocket costs for health care
4 among people with MS, excluding insurance premiums, were
5 almost twice as much as the general population. The costs
6 associated with MS increase with greater disability. Costs
7 for severely disabled individuals are more than twice those
8 for persons with a relatively mild form of the disease. A
9 recent study of medical bankruptcy found that 62.1% of all
10 personal bankruptcies in the United States were related to
11 medical costs.

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

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

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

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

1 options that may be available; and

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

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

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

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

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

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

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

5 (f) The Task Force shall be entitled to call to its
6 assistance and avail itself of the services of the employees of
7 any State, county, or municipal department, board, bureau,
8 commission, or agency as it may require and as may be available
9 to it for its purposes.

10 (g) The Task Force may meet and hold hearings as it deems
11 appropriate.

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

14 (i) The Task Force shall report its findings and
15 recommendations to the Governor and to the General Assembly,
16 along with any legislative bills that it desires to recommend
17 for adoption by the General Assembly, no later than December
18 31, 2015.

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

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