

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 may meet and hold hearings as it deems  
6       appropriate.

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

9       (h) The Task Force shall report its findings and  
10       recommendations to the Governor and to the General Assembly,  
11       along with any legislative bills that it desires to recommend  
12       for adoption by the General Assembly, no later than December  
13       31, 2015.

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15       repealed on January 1, 2016.

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