



Sen. John J. Cullerton

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09800SB1640sam001

LRB098 10386 RPM 42374 a

1 AMENDMENT TO SENATE BILL 1640

2 AMENDMENT NO. _____. Amend Senate Bill 1640 by replacing
3 everything after the enacting clause with the following:

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

1 tissues. MS damages the nerve-insulating myelin sheath
2 that surrounds and protects the brain. The damage to the
3 myelin sheath slows down or blocks messages between the
4 brain and the body.

5 (2) Most people experience their first symptoms of MS
6 between the ages of 20 and 40, but MS can appear in young
7 children and teens as well as much older adults. MS
8 symptoms can include visual disturbances, muscle weakness,
9 trouble with coordination and balance, sensations such as
10 numbness, prickling or pins and needles, and thought and
11 memory problems. MS patients can also experience partial or
12 complete paralysis, speech impediments, tremors,
13 dizziness, stiffness and spasms, fatigue, paresthesias,
14 pain, and loss of sensation.

15 (3) The cause of MS remains unknown; however, having a
16 first-degree relative, such as a parent or sibling, with MS
17 significantly increases a person's risk of developing the
18 disease. According to the National Institute of
19 Neurological Disorders and Stroke, it is estimated that
20 there are approximately 250,000 to 350,000 persons in the
21 United States who are diagnosed with MS. This estimate
22 suggests that approximately 200 new cases are diagnosed
23 each week. Other sources report a population of at least
24 400,000 in the United States. The estimate of persons with
25 MS in Illinois is 20,000, with at least 2 areas of MS
26 clusters identified in Illinois.

1 (4) Presently, there is no cure for MS. The complex and
2 variable nature of the disease makes it very difficult to
3 diagnose, treat, and research. The cost to the family,
4 often with young children, can be overwhelming. Among
5 common diagnoses, non-stroke neurologic illnesses, such as
6 multiple sclerosis, were associated with the highest
7 out-of-pocket expenditures (a mean of \$34,167), followed
8 by diabetes (\$26,971), injuries (\$25,096), stroke
9 (\$23,380), mental illnesses (\$23,178), and heart disease
10 (\$21,955). Median out-of-pocket costs for health care
11 among people with MS, excluding insurance premiums, were
12 almost twice as much as the general population. The costs
13 associated with MS increase with greater disability. Costs
14 for severely disabled individuals are more than twice those
15 for persons with a relatively mild form of the disease. A
16 recent study of medical bankruptcy found that 62.1% of all
17 personal bankruptcies in the United States were related to
18 medical costs.

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

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

26 (1) develop strategies to identify and address the

1 unmet needs of persons with MS in order to enhance the
2 quality of life of persons with MS by maximizing
3 productivity and independence and addressing emotional,
4 social, financial, and vocational challenges of persons
5 with MS; and

6 (2) develop strategies to provide persons with MS
7 greater access to various treatments and other therapeutic
8 options that may be available.

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

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

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

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

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

6 (e) The public members shall serve without compensation,
7 but shall be reimbursed for necessary expenses incurred in the
8 performance of their duties and within the limits of funds
9 available to the Task Force.

10 (f) The Task Force shall be entitled to call to its
11 assistance and avail itself of the services of the employees of
12 any State, county, or municipal department, board, bureau,
13 commission, or agency as it may require and as may be available
14 to it for its purposes.

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

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

19 (i) The Task Force shall report its findings and
20 recommendations to the Governor and to the General Assembly,
21 along with any legislative bills that it desires to recommend
22 for adoption by the General Assembly, no later than December
23 31, 2015.

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

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