



99TH GENERAL ASSEMBLY

State of Illinois

2015 and 2016

HB4576

by Rep. Sonya M. Harper

SYNOPSIS AS INTRODUCED:

New Act

Creates the Rare Disease Commission Act. Provides for the creation of the Rare Disease Commission. Defines terms. Provides that initial appointments shall be made by February 1, 2017. Provides required criteria and considerations for appointees and nominations to the Commission. Includes provisions regarding the terms, vacancies, and compensation for the Commission's membership. Requires that the Commission meet at least quarterly and submit an annual report due no later than December 31 of every year to the General Assembly. Provides that the Department of Public Health shall provide administrative and other support to the Commission. Effective January 1, 2017.

LRB099 17088 MJP 41446 b

FISCAL NOTE ACT
MAY APPLY

A BILL FOR

1 AN ACT concerning health.

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

4 Section 1. Short title. This Act may be cited as the Rare
5 Disease Commission Act.

6 Section 5. Definitions. As used in this Act, unless the
7 context requires otherwise:

8 "Chairperson" means the Chairperson of the Rare Disease
9 Commission.

10 "Commission" means the Rare Disease Commission.

11 "Rare disease" means a disease that affects less than
12 200,000 people in the United States.

13 "Relative" means a spouse, parent, parent-in-law, sibling,
14 sibling-in-law, child, child-in-law, grandparent, aunt, or
15 uncle.

16 "Vice-Chairperson" means the Vice-Chairperson of the Rare
17 Disease Commission.

18 Section 10. Commission created; membership.

19 (a) There is created the Rare Disease Commission to advise
20 the State on issues pertaining to the care and treatment of
21 individuals with rare diseases.

22 (b) The Commission shall be composed of 15 members:

1 (1) Eleven members shall be appointed by the Governor
2 from residents of the State whose position, knowledge, or
3 experience enables them to reasonably represent the
4 concerns, needs, and recommendations of those with rare
5 diseases, including physicians or health care providers
6 who treat patients with rare diseases. At a minimum, 5
7 members of the Commission shall be persons who either have
8 a rare disease or are a family member of a person living
9 with a rare disease. In making the appointments under this
10 paragraph (1), the Governor shall consider nominations
11 made by advocacy groups for rare diseases and
12 community-based organizations.

13 (2) One member of the Senate appointed by the President
14 of the Senate.

15 (3) One member of the Senate appointed by the Minority
16 Leader of the Senate.

17 (4) One member of the House of Representatives
18 appointed by the Speaker of the House of Representatives.

19 (5) One member of the House of Representatives
20 appointed by the Minority Leader of the House of
21 Representatives.

22 (c) The Chairperson of the Commission shall be elected from
23 the Commission's membership by a simple majority vote of the
24 total membership of the Commission. The Vice-Chairperson of the
25 Commission shall be elected from the Commission's membership by
26 a simple majority vote of the total membership of the

1 Commission.

2 (d) The Governor, President of the Senate, Minority Leader
3 of the Senate, Speaker of the House of Representatives, and
4 Minority Leader of the House of Representatives shall make
5 their initial appointments to the Commission by February 1,
6 2017.

7 (e) Of the initial members appointed by the Governor, 3
8 shall be appointed to terms of one year, 4 shall be appointed
9 to terms of 2 years, and 4 shall be appointed to terms of 3
10 years. Thereafter, all members shall be appointed for terms of
11 3 years. No member shall serve more than 2 consecutive terms. A
12 member shall serve until his or her successor is appointed and
13 qualified. Initial members' terms of office shall be chosen by
14 lot at the initial meeting of the Commission.

15 (f) Vacancies in Commission membership shall be filled in
16 the same manner as initial appointments. Appointments to fill
17 vacancies occurring before the expiration of a term shall be
18 for the remainder of the unexpired term.

19 (g) Members shall not receive compensation for their
20 services, but shall be reimbursed for their actual expenses
21 incurred in the performance of their duties plus up to \$50 per
22 day for any actual loss of wages incurred in the performance of
23 their duties.

24 (h) Total membership of the Commission consists of the
25 number of members serving on the Commission not including any
26 vacant positions. A quorum shall consist of a simple majority

1 of total membership and shall be sufficient to conduct the
2 transaction of business of the Commission, unless stipulated
3 otherwise in the by-laws of the Commission.

4 (j) The Commission shall meet at least quarterly.

5 Section 15. Study; recommendations. The Commission shall
6 make recommendations to the General Assembly, in the form of an
7 annual report, regarding:

8 (1) the use of prescription drugs and innovative
9 therapies for children and adults with rare diseases, and
10 specific subpopulations of children or adults with rare
11 diseases, as appropriate, together with recommendations on
12 the ways in which this information should be used in
13 specific State programs that (A) provide assistance or
14 health care coverage to individuals with rare diseases or
15 broader populations that include individuals with rare
16 diseases, or (B) have responsibilities associated with
17 promoting the quality of care for individuals with rare
18 diseases or broader populations that include individuals
19 with rare diseases;

20 (2) legislation that could improve the care and
21 treatment of adults or children with rare diseases;

22 (3) screening of newborn children for the presence of
23 genetic disorders; and

24 (4) any other issues the Commission considers
25 appropriate.

1 The Commission shall submit its annual report to the
2 General Assembly no later than December 31 of each year.

3 Section 20. Administrative support. The Department of
4 Public Health shall provide administrative and other support to
5 the Commission.

6 Section 99. Effective date. This Act takes effect January
7 1, 2017.