

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) All members shall be appointed for terms of 3 years. No
8 member shall serve more than 2 consecutive terms. A member
9 shall serve until his or her successor is appointed and
10 qualified.

11 (f) Vacancies in Commission membership shall be filled in
12 the same manner as initial appointments. Appointments to fill
13 vacancies occurring before the expiration of a term shall be
14 for the remainder of the unexpired term.

15 (g) Total membership of the Commission consists of the
16 number of members serving on the Commission not including any
17 vacant positions. A quorum shall consist of a simple majority
18 of total membership and shall be sufficient to conduct the
19 transaction of business of the Commission, unless stipulated
20 otherwise in the by-laws of the Commission.

21 (h) The Commission shall meet at least quarterly.

22 Section 15. Study; recommendations. The Commission shall
23 make recommendations to the General Assembly, in the form of an
24 annual report through 2020, regarding:

25 (1) the use of prescription drugs and innovative

1 therapies for children and adults with rare diseases, and
2 specific subpopulations of children or adults with rare
3 diseases, as appropriate, together with recommendations on
4 the ways in which this information should be used in
5 specific State programs that (A) provide assistance or
6 health care coverage to individuals with rare diseases or
7 broader populations that include individuals with rare
8 diseases, or (B) have responsibilities associated with
9 promoting the quality of care for individuals with rare
10 diseases or broader populations that include individuals
11 with rare diseases;

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

14 (3) in coordination with the Genetic and Metabolic
15 Diseases Advisory Committee, the screening of newborn
16 children for the presence of genetic disorders; and

17 (4) any other issues the Commission considers
18 appropriate.

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

21 Section 20. Administrative support. The Department of
22 Public Health shall provide administrative and other support to
23 the Commission.

24 Section 90. Repeal. This Act is repealed on January 1,

1 2020.

2 Section 99. Effective date. This Act takes effect January
3 1, 2017.