

AN ACT concerning health.

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

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

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

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

"Commission" means the Rare Disease Commission.

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

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

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

Section 10. Commission created; membership.

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

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

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

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

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

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

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

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

Commission.

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

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

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

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

(h) The Commission shall meet at least quarterly.

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

(1) the use of prescription drugs and innovative

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

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

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

(4) any other issues the Commission considers appropriate.

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

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

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

Public Act 099-0773

HB4576 Enrolled

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2020.

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