

HOUSE BILL NO. 5465

February 05, 2020, Introduced by Reps. Vaupel, Hammoud, Hertel, Miller, Whitsett and Koleszar and referred to the Committee on Health Policy.

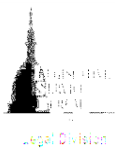
A bill to establish a rare disease review committee within the department of health and human services and to prescribe its powers and duties; and to prescribe the powers and duties of certain state officers and entities.

THE PEOPLE OF THE STATE OF MICHIGAN ENACT:

1 Sec. 1. As used in this act:

2 (a) "Committee" means the rare disease review committee
3 created in section 3.

4 (b) "Department" means the department of health and human
5 services.



1 (c) "Director" means the director of the department.

2 (d) "Rare disease" means a disease or condition that affects
3 less than 200,000 individuals in the United States at any 1 time.

4 Sec. 3. (1) The rare disease review committee is created
5 within the department.

6 (2) The committee consists of the following 9 members,
7 appointed by the governor as follows:

8 (a) Two members representing the department.

9 (b) One physician who is licensed under part 170 or 175 of the
10 public health code, 1978 PA 368, MCL 333.17001 to 333.17097 and
11 333.17501 to 333.17556.

12 (c) One individual who is selected from a list of nominees
13 submitted by the senate majority leader.

14 (d) One individual who is selected from a list of nominees
15 submitted by the speaker of the house of representatives.

16 (e) One registered professional nurse who is licensed under
17 part 172 of the public health code, 1978 PA 368, MCL 333.17201 to
18 333.17242.

19 (f) One licensed bachelor's social worker or licensed master's
20 social worker who is licensed under part 185 of the public health
21 code, 1978 PA 368, MCL 333.18501 to 333.18518.

22 (g) Two members of the public.

23 (3) The governor shall appoint the first members to the
24 committee by January 1, 2021.

25 (4) Members of the committee serve for terms of 2 years or
26 until a successor is appointed, whichever is later, except that of
27 the members first appointed 4 must serve for 1 year.

28 (5) If a vacancy occurs on the committee, the governor shall
29 make an appointment for the unexpired term in the same manner as



1 the original appointment.

2 (6) The governor may remove a member of the committee for
3 incompetence, dereliction of duty, malfeasance, misfeasance, or
4 nonfeasance in office, or any other good cause.

5 (7) The governor shall call the first meeting of the
6 committee. At the first meeting, the committee shall elect a
7 chairperson from among the members appointed under subsection
8 (2)(a) and shall elect other officers as it considers necessary or
9 appropriate. After the first meeting, the committee shall meet at
10 least quarterly, or more frequently at the call of the chairperson
11 or if requested by a majority of the members of the committee.

12 (8) A majority of the members of the committee constitute a
13 quorum for the transaction of business at a meeting of the
14 committee. A majority of the members present and serving are
15 required for official action of the committee.

16 (9) The business that the committee performs must be conducted
17 at a public meeting of the committee held in compliance with the
18 open meetings act, 1976 PA 267, MCL 15.261 to 15.275.

19 (10) A writing prepared, owned, used, in the possession of, or
20 retained by the committee in the performance of an official
21 function is subject to the freedom of information act, 1976 PA 442,
22 MCL 15.231 to 15.246.

23 (11) Members of the committee serve without compensation.
24 However, members of the committee may be reimbursed for their
25 actual and necessary expenses incurred in the performance of their
26 official duties as members of the committee.

27 Sec. 5. (1) The committee shall develop a list of rare
28 diseases for purposes of this act and make the list available to
29 the public by posting the list on the department's website. The



1 committee shall biennially review the list and make any updates to
2 the list that the committee determines necessary or appropriate.

3 (2) Subject to subsections (3) and (4), the committee shall
4 annually select at least 1 rare disease from the list described in
5 subsection (1) and do all of the following:

6 (a) Make findings on the prevalence of the rare disease in
7 this state.

8 (b) Make findings on the estimated overall cost of the rare
9 disease over the course of 1 year.

10 (c) Make any other finding on the rare disease that the
11 committee considers relevant.

12 (d) Develop recommendations on legislation to address the
13 findings described in subdivisions (a), (b), and (c).

14 (3) When selecting a rare disease under subsection (2), the
15 committee shall consider each of the following rare diseases and
16 determine whether any of the following rare diseases should be
17 prioritized over another rare disease occurring in the United
18 States that is on the list described in subsection (1):

19 (a) Spina bifida.

20 (b) Krabbe disease.

21 (c) Cystic fibrosis.

22 (d) A pediatric autoimmune neuropsychiatric disorder if the
23 disorder is considered a rare disease.

24 (e) Long QT syndrome.

25 (f) Cytomegalovirus.

26 (4) In making findings and developing recommendations under
27 subsection (2), the committee shall consult with persons that
28 specialize in the rare disease.

29 (5) By September 30, 2021 and annually thereafter, the



1 committee shall prepare a report of the findings and
2 recommendations described in subsection (2) and shall submit the
3 report to the standing committees of the house of representatives
4 and senate on health policy.

5 (6) The director shall ensure that each report prepared by the
6 committee is made available to the public on the department's
7 website for at least 4 years.

