

**SUBSTITUTE FOR
HOUSE BILL NO. 4167**

A bill to amend 1978 PA 368, entitled
"Public health code,"
(MCL 333.1101 to 333.25211) by adding sections 5135 and 5135a.

THE PEOPLE OF THE STATE OF MICHIGAN ENACT:

1 **Sec. 5135. (1) The rare disease advisory council is created**
2 **within the department for the purpose of advising the department**
3 **and other state agencies on research, diagnosis, and treatment**
4 **efforts related to rare diseases in this state.**

5 **(2) The council must consist of the following members:**

6 **(a) The director or the director's designee.**

7 **(b) All of the following appointed by the director:**

8 **(i) One physician licensed under part 170 or 175 who has**
9 **experience treating patients with rare diseases.**

1 (ii) One registered professional nurse licensed under part 172
2 who has expertise in providing care to patients with rare diseases.

3 (iii) An epidemiologist who practices in this state who has
4 expertise in the incidence, prevalence, and control of rare
5 diseases.

6 (iv) One individual who represents a hospital located in this
7 state. The individual appointed under this subparagraph may not be
8 from the same institution as the individual appointed under
9 subparagraph (viii) .

10 (v) One individual representing a health insurer.

11 (vi) One individual representing a health maintenance
12 organization.

13 (vii) One individual representing the biopharmaceutical
14 industry in this state.

15 (viii) One individual who engages in rare disease research.

16 (ix) Two parents or guardians of children with a rare disease.
17 Each parent or guardian appointed under this subparagraph must
18 represent a different family.

19 (x) Three individuals with a rare disease. Each individual
20 appointed under this subparagraph must have a different rare
21 disease.

22 (xi) Two individuals representing rare disease patient
23 organizations that operate in this state. Each individual appointed
24 under this subparagraph must represent a different organization.

25 (xii) A medical ethicist who practices in this state.

26 (xiii) A representative from the national pharmaceutical
27 industry or a pharmaceutical company working in the area of rare
28 diseases.

1 (xiv) A genetic counselor licensed under part 170 who is
2 familiar with rare diseases.

3 (3) Subject to subsection (13), the director may appoint
4 additional members to the council that the director considers
5 necessary or appropriate.

6 (4) The members first appointed to the council must be
7 appointed within 90 days after the effective date of the amendatory
8 act that added this section.

9 (5) Members of the council serve for terms of 4 years or until
10 a successor is appointed, whichever is later.

11 (6) A vacancy on the council must be filled in the same manner
12 as the original appointment. An individual appointed to fill a
13 vacancy created other than by expiration of a term must be
14 appointed for the unexpired term of the member whom the individual
15 is to succeed in the same manner as the original appointment.

16 (7) The director may remove a member of the council for
17 incompetence, dereliction of duty, malfeasance, misfeasance, or
18 nonfeasance in office, or any other good cause.

19 (8) The director shall call the first meeting of the council.
20 At the first meeting, the council shall elect from among its
21 members a chairperson and may elect other officers as it considers
22 necessary or appropriate. The council shall meet at least
23 quarterly, or more frequently at the call of the chairperson or at
24 the request of 4 or more members.

25 (9) A majority of the members of the council constitute a
26 quorum for the transaction of business. A majority of the members
27 present and serving are required for official action of the
28 council.

29 (10) The council shall conduct its business in compliance with

1 the open meetings act, 1976 PA 267, MCL 15.261 to 15.275.

2 (11) A writing that is prepared, owned, used, possessed, or
3 retained by the council in performing an official function is
4 subject to the freedom of information act, 1976 PA 442, MCL 15.231
5 to 15.246.

6 (12) A member of the council is not entitled to compensation,
7 but must be reimbursed for the member's necessary travel expenses
8 for attendance in accordance with section 1216.

9 (13) At any time, the council may make recommendations to the
10 director on the appointment of additional members to the council
11 that the council considers necessary to carry out its duties.

12 (14) As used in this section and section 5135a:

13 (a) "Council" means the rare disease advisory council created
14 in subsection (1).

15 (b) "Rare disease" means a disease that affects fewer than
16 200,000 individuals in the United States.

17 Sec. 5135a. (1) The council may do 1 or more of the following:

18 (a) Subject to appropriation, apply for and accept grants and
19 gifts from government, nonprofit, and private sources. The
20 department shall provide clerical and administrative assistance to
21 the council in applying for grants under this subdivision, as the
22 director considers necessary or appropriate.

23 (b) Hold public hearings and make inquiries and receive
24 comments from the general public to assist the council in
25 developing recommendations under this section.

26 (c) Consult with experts on rare diseases to assist the
27 council in developing recommendations under this section,
28 including, but not limited to, experts from the private sector,
29 organized labor groups, government agencies, and institutions of

1 higher education.

2 (2) The council shall do all of the following:

3 (a) Research and identify priorities relating to the cost-
4 effectiveness of and access to treatments and services provided to
5 individuals with rare diseases in this state, and develop policy
6 recommendations aimed at preventing discrimination against
7 individuals with rare diseases with respect to the cost-
8 effectiveness of and access to treatments and services and other
9 related issues.

10 (b) Identify best practices for rare diseases from other
11 states and at the national level that could improve the education,
12 care, and treatment of, and services and supports provided to,
13 adults and minors with rare diseases in this state.

14 (c) Coordinate with other rare disease advisory bodies,
15 community-based organizations, and other public and private
16 organizations in performing its duties under this section to ensure
17 greater cooperation between this state, other states, and the
18 federal government regarding the research, diagnosis, and treatment
19 of rare diseases, by disseminating the council's research,
20 findings, and recommendations when appropriate.

21 (d) Serve as an advisory body on rare diseases to the
22 legislature, the governor, the department, and other state
23 agencies.

24 (e) Research and make recommendations to the legislature and
25 the department on the most appropriate method to collect data on
26 rare diseases.

27 (f) Provide information or advice on rare diseases to the
28 department or governor, as the director or governor considers
29 necessary or appropriate.

1 (g) By December 21, 2023, assist the department in developing
2 a publicly accessible webpage on the department's website on rare
3 disease resources. The webpage must include a list of rare diseases
4 that predominately affect geographically disadvantaged communities
5 and content on rare diseases, including, but not limited to, links
6 to websites on rare diseases and resources on rare diseases that
7 the council and the department consider useful to individuals with
8 rare diseases and the general public. The council shall annually
9 review and recommend changes to the webpage to the department.

10 (h) Investigate rare diseases from the list described in
11 subdivision (g) and make recommendations to the legislature on the
12 rare disease.

13 (i) Beginning December 21, 2023, and by December 21 of every
14 other year beginning after the first report is submitted to the
15 legislature under this subdivision, submit a written report to the
16 legislature on the activities, findings, and recommendations of the
17 council.

18 (3) Any findings and recommendations made by the council under
19 this section must be based on medical or scientific evidence.

20 Enacting section 1. This amendatory act takes effect 90 days
21 after the date it is enacted into law.