

HOUSE BILL NO. 4654

April 15, 2021, Introduced by Reps. Clemente, Pohutsky, Sneller, Aiyash, Sowerby, Hood, Brabec, Steckloff, Stone, Manoogian, Rogers, Witwer, Ellison, Kuppa, Hertel, Whitsett and Coleman and referred to the Committee on Health Policy.

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.**

3 **(2) The council shall consist of the director, or his or her**
4 **designee, and the following members, appointed by the governor:**

5 **(a) One researcher who specializes in rare diseases.**

1 (b) Two individuals with a rare disease or who are parents or
2 caregivers of an individual with a rare disease.

3 (c) One representative of health care industries operating in
4 this state that support the care and treatment of individuals with
5 rare diseases.

6 (d) Two representatives from rare disease patient
7 organizations in this state.

8 (e) One health care professional who has expertise in treating
9 patients with rare diseases.

10 (3) Subject to subsection (13), the governor may appoint
11 additional members to the council that the governor considers
12 necessary or appropriate.

13 (4) The members first appointed to the council must be
14 appointed within 90 days after the effective date of this section.

15 (5) Members of the council shall serve for terms of 4 years or
16 until a successor is appointed, whichever is later, except that of
17 the members first appointed 3 shall serve for 1 year, 3 shall serve
18 for 2 years, and 1 shall serve for 3 years.

19 (6) A vacancy on the council must be filled in the same manner
20 as the original appointment. An individual appointed to fill a
21 vacancy created other than by expiration of a term must be
22 appointed for the unexpired term of the member whom he or she is to
23 succeed in the same manner as the original appointment.

24 (7) The governor may remove a member of the council for
25 incompetence, dereliction of duty, malfeasance, misfeasance, or
26 nonfeasance in office, or any other good cause.

27 (8) The director shall call the first meeting of the council.
28 At the first meeting, the council shall elect from among its
29 members a chairperson and other officers as it considers necessary

1 or appropriate. After the first meeting, the council shall meet at
2 least quarterly, or more frequently at the call of the chairperson
3 or if requested by 4 or more members.

4 (9) A majority of the members of the council constitute a
5 quorum for the transaction of business at a meeting of the council.
6 A majority of the members present and serving are required for
7 official action of the council.

8 (10) The business that the council may perform must be
9 conducted at a public meeting of the council held in compliance
10 with the open meetings act, 1976 PA 267, MCL 15.261 to 15.275.

11 (11) A writing prepared, owned, used, in the possession of, or
12 retained by the council in the performance of an official function
13 is subject to the freedom of information act, 1976 PA 442, MCL
14 15.231 to 15.246.

15 (12) Members of the council shall serve without compensation.
16 However, members of the council may be reimbursed for their actual
17 and necessary expenses incurred in the performance of their
18 official duties as members of the council.

19 (13) At or after the first meeting of the council, the council
20 may make recommendations to the governor on the appointment of
21 additional members to the council that the council considers
22 necessary or appropriate to carry out its duties.

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

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

26 (b) "Rare disease" means a disease that affects fewer than
27 200,000 individuals in the United States.

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

29 (a) Apply for and accept grants and gifts from government and

1 private sources. The department shall provide clerical and
2 administrative assistance to the council in applying for grants
3 under this subdivision, as the director considers necessary or
4 appropriate.

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

8 (c) Consult with experts on rare diseases to assist the
9 council in developing recommendations under this section,
10 including, but not limited to, experts from the private sector,
11 organized labor groups, government agencies, and institutions of
12 higher education.

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

14 (a) Research and identify priorities relating to the cost-
15 effectiveness of and access to treatments and services provided to
16 individuals with rare diseases in this state, and develop policy
17 recommendations aimed at preventing discrimination against
18 individuals with rare diseases with respect to the cost-
19 effectiveness of and access to treatments and services and other
20 related issues.

21 (b) Identify best practices for rare diseases from other
22 states and at the national level that could improve the education,
23 care, and treatment of adults and minors with rare diseases in this
24 state.

25 (c) Coordinate with other rare disease advisory bodies,
26 community-based organizations, and other public and private
27 organizations in performing its duties under this section to ensure
28 greater cooperation between this state, other states, and the
29 federal government regarding the research, diagnosis, and treatment

1 of rare diseases, by disseminating the council's research,
2 findings, and recommendations when appropriate.

3 (d) Serve as an advisory body on rare diseases to the
4 legislature, the department, and the governor.

5 (e) Research and make recommendations to the legislature on
6 the most appropriate method to collect data on rare diseases.

7 (f) Provide information or advice on rare diseases to the
8 department or governor, as the director or governor considers
9 necessary or appropriate.

10 (g) Beginning December 31, 2021, and by December 31 of every
11 other year beginning after the first report is submitted to the
12 legislature under this subdivision, submit a written report to the
13 legislature on the activities, findings, and recommendations of the
14 council.

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