

# HOUSE BILL NO. 4169

March 05, 2025, Introduced by Reps. Morgan, Dievendorf, Paiz, Rheingans, Foreman, Koleszar, McFall, Martus, Conlin, Xiong, Tsernoglou, Byrnes, B. Carter, MacDonell, Brixie, Edwards, Hoskins, Rogers, Miller, Mentzer, Arbit, Breen, Wilson, Wegela, McKinney, Scott, Wooden, Glanville, Myers-Phillips, Skaggs, Young, Weiss, Longjohn, Steckloff, Witwer, Alexander and Farhat and referred to 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 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 director. Except as  
6 otherwise provided in subsection (3), the council must also consist

1 of a total of not fewer than 12 and not more than 18 additional  
2 members who are appointed by the director. In appointing members to  
3 the council, the director shall select from any of the following:

4 (a) One physician licensed under part 170 or 175 who has  
5 experience treating patients with rare diseases.

6 (b) One registered professional nurse licensed under part 172  
7 who has expertise in providing care to patients with rare diseases.

8 (c) One epidemiologist who practices in this state and who has  
9 expertise in the incidence, prevalence, and control of rare  
10 diseases.

11 (d) One individual who represents a hospital located in this  
12 state. If an individual is appointed under this subdivision and  
13 subdivision (c), the individual appointed under this subdivision  
14 may not be from the same institution as the individual appointed  
15 under subdivision (c).

16 (e) One individual representing a health insurer.

17 (f) One individual representing a health maintenance  
18 organization.

19 (g) One individual representing the biopharmaceutical industry  
20 in this state.

21 (h) One individual who engages in rare disease research.

22 (i) Not more than 2 parents or guardians of children with a  
23 rare disease. If more than 1 parent or guardian is appointed under  
24 this subdivision, each parent or guardian must represent a  
25 different family.

26 (j) Not more than 3 individuals with a rare disease. If more  
27 than 1 individual is appointed under this subdivision, each  
28 individual must have a different rare disease.

29 (k) Not more than 2 individuals representing rare disease

1 patient organizations that operate in this state. If more than 1  
2 individual is appointed under this subdivision, each individual  
3 must represent a different organization.

4 (l) One medical ethicist who practices in this state.

5 (m) One representative from the national pharmaceutical  
6 industry or a pharmaceutical company working in the area of rare  
7 diseases.

8 (n) One genetic counselor licensed under part 170 who is  
9 familiar with rare diseases.

10 (3) The director may appoint additional members to the council  
11 that the director considers necessary or appropriate.

12 (4) The members first appointed to the council must be  
13 appointed not later than 90 days after the effective date of the  
14 amendatory act that added this section.

15 (5) Members of the council serve for terms of not more than 4  
16 years.

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

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

25 (8) The director shall call the first meeting of the council.  
26 At the first meeting, the council shall elect from among its  
27 members a chairperson and may elect other officers as it considers  
28 necessary or appropriate. The council shall meet at least  
29 quarterly, or more frequently at the call of the chairperson or at

1 the request of 4 or more members.

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

6 (10) The council shall conduct its business in compliance with  
7 the open meetings act, 1976 PA 267, MCL 15.261 to 15.275.

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

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

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

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

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

21 (b) "Rare disease" means a disease that affects fewer than  
22 200,000 individuals in the United States.

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

24 (a) Subject to appropriation, apply for and accept grants and  
25 gifts from government, nonprofit, and private sources. The  
26 department shall provide clerical and administrative assistance to  
27 the council in applying for grants under this subdivision, as the  
28 director considers necessary or appropriate.

29 (b) Hold public hearings and make inquiries and receive

1 comments from the general public to assist the council in  
2 developing recommendations under this section.

3 (c) Consult with experts on rare diseases to assist the  
4 council in developing recommendations under this section,  
5 including, but not limited to, experts from the private sector,  
6 organized labor groups, government agencies, and institutions of  
7 higher education.

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

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

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

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

27 (d) Serve as an advisory body on rare diseases to the  
28 legislature, the governor, the department, and other state  
29 agencies.

1           (e) Research and make recommendations to the legislature and  
2 the department on the most appropriate method to collect data on  
3 rare diseases.

4           (f) Provide information or advice on rare diseases to the  
5 department or governor, as the director or governor considers  
6 necessary or appropriate.

7           (g) By March 31, 2026, assist the department in developing a  
8 publicly accessible webpage on the department's website on rare  
9 disease resources. The webpage must include information about  
10 inequities experienced by individuals with rare diseases,  
11 including, but not limited to, links to websites on rare diseases  
12 and resources on rare diseases that the council and the department  
13 consider useful to individuals with rare diseases and the general  
14 public. The council shall annually review and recommend changes to  
15 the webpage to the department.

16           (h) Investigate rare diseases and make recommendations to the  
17 legislature.

18           (i) Beginning March 31, 2026, and by March 31 of every other  
19 year beginning after the first report is submitted to the  
20 legislature under this subdivision, submit a written report to the  
21 legislature on the activities, findings, and recommendations of the  
22 council.

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

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