

RARE DISEASE ADVISORY COUNCIL

Phone: (517) 373-8080
<http://www.house.mi.gov/hfa>

House Bill 4654 as introduced
Sponsor: Rep. Cara Clemente
Committee: Health Policy
Revised 10-11-21

Analysis available at
<http://www.legislature.mi.gov>

SUMMARY:

House Bill 4654 would add two sections to Article 5 (Prevention and Control of Diseases and Disabilities) of the Public Health Code to create the Rare Disease Advisory Council within the Department of Health and Human Services (DHHS).

Rare disease would mean a disease or condition that affects fewer than 200,000 individuals in the United States.

Council members would include the DHHS director or a designee and the following, appointed by the governor:

- One researcher who specializes in rare diseases.
- Two individuals with a rare disease or who are a parent or caregiver of an individual with a rare disease.
- One representative of health care industries operating in Michigan that support the care and treatment of individuals with rare diseases.
- If determined necessary by the council once it convenes, the governor could appoint additional members that the governor considers necessary or appropriate.

The governor would have to appoint the initial members within 90 days of the bill's effective date. Members would serve for four-year terms (except that three of the initial members would serve one-year terms, three would serve two-year terms, and one would serve a three-year term), and vacancies would be filled in the same way as that position was filled originally. The governor could remove members for incompetence, dereliction of duty, malfeasance, misfeasance, or nonfeasance in office, or any other good cause.

After the DHHS director called the initial meeting, members would elect a chairperson and any other officers at that meeting and meet at least quarterly thereafter. Meetings would have to be held in compliance with the Open Meetings Act, and writings would have to be made available to the public in compliance with the Freedom of Information Act. Members would serve without compensation but could be reimbursed for actual and necessary expenses.

The council could do one or more of the following:

- Apply for and accept grants and gifts from government and private sources. (DHHS would provide assistance in applying as the DHHS director determined necessary and appropriate.)
- Hold public hearings and make inquiries and receive comments from the general public to assist the council in developing recommendations.
- Consult with experts on rare diseases to assist in developing recommendations.

The council would have to do all of the following:

- Research and identify priorities relating to the cost-effectiveness of and access to treatments and services provided to individuals with rare diseases in Michigan and develop policy recommendations aimed at preventing discrimination against those individuals with respect to the cost-effectiveness of and access to treatments and services and other related issues.
- Identify best practices for rare diseases from other states and at the national level that could improve the education, care, and treatment of adults and minors with rare diseases in Michigan.
- Coordinate with other rare disease advisory bodies and organizations in performing its duties to ensure greater cooperation between Michigan, other states, and the federal government regarding the research, diagnosis, and treatment of rare diseases, by disseminating the council's research, findings, and recommendations when appropriate.
- Serve as an advisory body on rare diseases to the legislature, DHHS, and the governor.
- Research and make recommendations to the legislature on the most appropriate method to collect data on rare diseases.
- Provide information or advice on rare diseases to DHHS or the governor as needed.

By December 31, 2021, and yearly thereafter, the council would have to submit a report to the legislature on its activities, findings, and recommendations.

The bill would take effect 90 days after enactment.

FISCAL IMPACT:

House Bill 4654 has fiscal cost implications of approximately \$100,000 to \$200,000 annually for DHHS. The bill requires DHHS to establish and support a new Rare Disease Advisory Council, with responsibility to investigate rare disease costs, access, and best practices, hold public hearings, consult with experts, seek grants, and annually report to the legislature on findings and recommendations. The cost to DHHS would be partly dependent on the activity level of the committee, which is required to meet at least quarterly. Members would not be compensated but could be reimbursed for expenses.

The Fiscal Year 2020-21 DHHS budget included a new appropriation of \$70,000 GF/GP and boilerplate to support a similar rare disease review committee. The funding is continued in the recently enacted FY 2021-22 DHHS budget, 2021 PA 87, and related boilerplate Sec. 1240 is revised to support the Rare Disease Advisory Council.

The bill would have no fiscal impact on local units of government

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■ This analysis was prepared by nonpartisan House Fiscal Agency staff for use by House members in their deliberations, and does not constitute an official statement of legislative intent.