

RARE DISEASE REVIEW COMMITTEE

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

House Bill 5465 as introduced
Sponsor: Rep. Hank Vaupel
Committee: Health Policy
Complete to 2-18-20

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

SUMMARY:

House Bill 5465 would create a new act, establishing a *rare disease* review committee 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 at any one time.

Committee members would be appointed by the governor and would consist of the following:

- Two members representing DHHS
- One medical or osteopathic doctor (M.D. or D.O.)
- One individual from a list submitted by the Senate Majority Leader
- One individual from a list submitted by the Speaker of the House of Representatives
- One registered professional nurse (R.N.)
- One licensed bachelor's or master's social worker
- Two members of the public

The governor would appoint the initial members by January 1, 2021. Members would serve for two-year terms (except that four of the initial members would serve one-year terms), 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.

Members would elect a chairperson and any other officers at the first meeting and would 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 committee would be charged with developing and posting a list of rare diseases on DHHS' website; the list would be reviewed and updated every two years.

Annually, the committee would select at least one rare disease from its list and make findings on its prevalence, overall costs over the course of a year, and any other findings it deems relevant, as well as recommend legislation for addressing those findings. When doing so, the committee would have to consult with applicable rare disease specialists. The

committee would have to prepare a report on its findings and submit it to the House of Representatives and Senate Health Policy committees. The DHHS director would have to ensure that the report be posted on the DHHS website for at least four years.

In selecting its annual rare disease for further study, the committee would have to consider each of the following and determine if any should be prioritized over another rare disease on its list:

- Spina bifida
- Krabbe disease
- Cystic fibrosis
- A pediatric autoimmune neuropsychiatric disorder if the disorder is considered a rare disease
- Long QT syndrome
- Cytomegalovirus

FISCAL IMPACT:

House Bill 5465 has fiscal cost implications of approximately \$70,000 to \$200,000 annually for DHHS. The bill requires DHHS to establish, chair, and support a new Rare Disease Review Committee, with responsibility to develop a list of rare diseases, post the list on the DHHS website, and update the list every two years and to annually investigate, consult with experts, and report to the legislature on one rare disease on the list and include legislative recommendations in the report. The cost to DHHS would be partly dependent on the activity level of the nine-member committee, which is required to meet at least quarterly. Members would not be compensated but may be reimbursed for expenses.

This estimate does not include costs to implement recommendations of the committee.

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.