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House Bill 4167 (Substitute S-1 as reported) Sponsor: Representative Jason Morgan

House Committee: Health Policy Senate Committee: Health Policy

## **CONTENT**

The bill would amend Chapter 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), and to prescribe its membership and duties.

The bill would take effect 90 days after its enactment.

Proposed MCL 333.5135 & 333.5135a

## **BRIEF RATIONALE**

According to testimony, many healthcare providers, educators, and policymakers are not informed about rare diseases that affect residents of Michigan. This lack of information on rare diseases may lead to uninformed decision-making. Accordingly, it has been suggested that the Council be created to serve as an informational resource on rare diseases and inform decision-making related to those rare diseases.

## **PREVIOUS LEGISLATION**

(This section does not provide a comprehensive account of previous legislative efforts on this subject matter.)

The bill is a reintroduction of House Bill 4654 from the 2021-2022 Legislative Session.

Legislative Analyst: Alex Krabill

## **FISCAL IMPACT**

The bill would have an indeterminate negative fiscal impact on the DHHS and no impact on local units of government. The Department would incur the costs for staff or support provided to the Council. Members of the Council would serve without compensation; however, they could be reimbursed for actual and necessary expenses incurred while serving.

The typical annual costs to support an advisory council can range from \$10,000 to \$200,000 depending on the travel expenses and staff demands of the Council. The Fiscal Year 2023-2024 DHHS budget, Public Act 119 of 2023, included a total of \$200,000 GF/GP (\$70,000 GF/GP in ongoing funding and \$130,000 in one-time funding) and boilerplate to support the efforts of the Council.

Date Completed: 11-8-23 Fiscal Analyst: Ellyn Ackerman