

Chapter 65

2019 Regular Session

Subject Advisory Council on Rare Diseases

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Overview

This act requests that the Board of Regents of the University of Minnesota establish a rare diseases advisory council at the university. A similar provision was included in Laws 2018, chapter 201, which was vetoed by the governor.

Summary

Section	Description
1	<p>Advisory council on rare diseases.</p> <p>Adds § 137.68. Requests the establishment of an advisory council on rare diseases at the University of Minnesota.</p> <p>Subd. 1. Establishment. Requests that the Board of Regents establish a Chloe Barnes Advisory Council on Rare Diseases at the University of Minnesota. Defines rare disease as any disease (1) that affects less than 200,000 people in the U.S., or (2) that affects more than 200,000 people in the U.S. and for which the cost of developing and making available a drug for that disease would not be recovered from the U.S. sales of that drug.</p> <p>Subd. 2. Membership. Lists suggested advisory council membership and provides for initial appointments.</p> <p>Subd. 3. Meetings. Requests the first meeting of the advisory council to occur by October 1, 2019, and requires it to meet at the call of the chair or the request of a majority of the council members.</p> <p>Subd. 4. Duties. Lists permitted duties for the advisory council.</p> <p>Subd. 5. Conflicts of interest. Makes advisory council members subject to the Board of Regents policy on conflicts of interest.</p> <p>Subd. 6. Annual report. Requires the advisory council to report by January 1 of each year beginning January 1, 2020, to certain legislative committees on the council's activities and other issues on which it chooses to report.</p>

Section	Description
2	Appropriation. Makes a \$150,000 appropriation in each year of the 2020-2021 biennium and 2022-2023 biennium from the general fund to the Board of Regents of the University of Minnesota for the advisory council on rare diseases.
3	Appropriations enacted more than once. Provides that if an appropriation in this act is enacted more than once in the 2019 legislative session, the appropriation must be given effect only once.



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