

THE FLORIDA SENATE
2021 SUMMARY OF LEGISLATION PASSED
Committee on Health Policy

CS/CS/SB 272 — Rare Disease Advisory Council

by Appropriations Committee; Health Policy Committee; and Senator Baxley

The bill creates s. 381.99, F.S., to establish the Rare Disease Advisory Council (Council) adjunct to the Department of Health (DOH). The Council is tasked with providing recommendations to improve the health outcomes of Floridians who have a rare disease, defined as a disease that affects fewer than 200,000 people in the United States. The bill establishes the membership of the Council, as well as the length of the members' terms. The bill requires that the Council first meet by October 1, 2021, and provide its recommendations to the Governor and the State Surgeon General by July 1 of each year beginning in 2022.

The Council is tasked with:

- Consulting with experts and soliciting public comment to develop recommendations on improving the treatment of rare diseases in Florida;
- Developing strategies for academic research institutions to facilitate continued research on rare diseases;
- Developing strategies for health care providers to be informed on how to recognize and treat patients with a rare disease; and
- Providing input and feedback to the DOH, the Medicaid program, and other state agencies on matters that affect people with a rare disease.

If approved by the Governor, these provisions take effect July 1, 2021.

Vote: Senate 39-0; House 117-0