

HCS HB 2407 -- ADVISORY COUNCIL ON RARE DISEASES

SPONSOR: Ruth

COMMITTEE ACTION: Voted "Do Pass with HCS" by the Standing Committee on Children and Families by a vote of 11 to 0. Voted "Do Pass" by the Rules- Legislative Oversight Committee by a vote of 12 to 0.

This bill establishes the "Advisory Council on Rare Diseases and Personalized Medicine" to serve as an expert advisory committee to the Drug Utilization Review Board. The advisory council shall be made up of health care professionals as specified in the bill. The first meeting of the advisory council shall be no later than February 28, 2019, and following the first meeting, the advisory council will meet upon request.

The bill requires the review board to seek the input of the advisory council on a variety of topics, as specified in the bill. Any recommendation of the advisory council must be made in writing and during a public hearing.

This bill requires all advisory council members to annually sign a conflict of interest statement and specifies that at least 20% of the members may not have a conflict of interest to any insurer, pharmaceutical benefits manager, or pharmaceutical manufacturer.

PROPOSERS: Supporters say that the Advisory Council on Rare Diseases and Personalized Medicine would be a specialized resource to aid the Drug Utilization Review Board and provide the board with insights and expertise on therapies and drugs to treat rare diseases.

Testifying for the bill were Representative Ruth; American Cancer Society Action Network; and the Missouri Biotechnology Association.

OPPOSERS: There was no opposition voiced to the committee.