

SS HB 1953 -- INFORMATION ON TREATMENT OF DISEASES

BONE MARROW REGISTRY

This bill requires the Department of Health and Senior Services to develop information regarding the bone marrow registry. A primary care provider or urgent care physician may inquire of a new patient who is 18 or older and under 45 whether he or she is registered with the bone marrow registry. If the patient is not registered, the provider or physician will provide the patient with the information on the registry provided by the department (Section 192.1120, RSMo).

ADVISORY COUNCIL ON RARE DISEASES

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 (Section 208.183).