

HB 1545 -- DESIGNATION OF PKS DAY

SPONSOR: Kirkton

COMMITTEE ACTION: Voted "do pass by consent" by the Committee on Health Care Policy by a vote of 11 to 0.

This bill designates December 4 of each year as "PKS Day." Pallister-Killian Mosaic Syndrome, commonly known as Pallister-Killian Syndrome or PKS, is a disorder usually caused by the presence of an abnormal extra chromosome and is characterized by vision and hearing impairments, seizure disorders, and early childhood, intellectual disability, distinctive facial features, sparse hair, areas of unusual skin coloring, weak muscle tone, and other birth defects. The bill recommends that the day be appropriately observed by participating in awareness and educational activities on the symptoms and impact of the syndrome and to support research, education, and community service programs.

FISCAL NOTE: No impact on state funds in FY 2013, FY 2014, and FY 2015.

PROPOSERS: Supporters say that PKS is a neurological disease and only about 200 cases are reported each year. There are three children in Missouri with this disease. The bill will raise awareness to help diagnose any undiagnosed cases. There is quite a big network of private entities that can be utilized to bring about awareness without any state cost. PKS is very difficult to diagnose because it is not detected in blood work, but rather by tissue sampling. Very few doctors know of this syndrome. Raising awareness could lead to different protocols to be used to detect this disease early. Delays in the diagnosis causes prolonged proper treatment. The bill helps with grant writing activities and could help advocates gain financial contributions to help families pay for services that are not covered by insurance.

Testifying for the bill were Representative Kirkton; Kate Hettiger; and Cammie Gray.

OPPOSERS: There was no opposition voiced to the committee.