

HCS HB 66 -- NEWBORN SCREENING REQUIREMENTS

SPONSOR: Ruth

COMMITTEE ACTION: Voted "Do Pass" by the Standing Committee on Health and Mental Health Policy by a vote of 10 to 0. Voted "Do Pass" by the committee on Rules- Administrative Oversight by a vote of 14 to 0.

This bill expands the newborn screening requirements to include spinal muscular atrophy (SMA) and Hunter syndrome (MPS II) and requires the Department of Health and Senior Services to apply for specified available newborn screening grant funding and gives the Department discretion in accepting the terms of such grants.

PROPOSERS: Supporters say that newborn screening is necessary for SMA and MPS II because timely treatment allows for much better outcomes. Without newborn screening it can take months to get a diagnosis. There is currently a new drug to treat SMA that was just approved by the Food and Drug Administration. Newborn screening would ensure timely treatment of SMA with the new drug, which requires early intervention for the greatest efficacy. There are also currently six drugs in clinical trials to obtain FDA approval.

Testifying for the bill were Representative Ruth; Grace Grutter; Leslie Derrington; Jackie Glasscock; Wildon Farwell, Biogen; and Missouri Chapter Of The Academy Of Pediatrics.

OPPOSERS: There was no opposition voiced to the committee.

OTHERS: Others testifying on the bill say that the March of Dimes is unable to take an official position until the screenings are on the National Recommended Uniform Screening Panel for Newborns (RUSP).

Testifying for informational purposes was the March of Dimes.