

MISSOURI SENATE

Rob Mayer 25th Senate District

JEFFERSON CITY

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Senate Gives Approval to Bill Advanced by Sen. Rob Mayer that Expands Newborn Screenings for Certain Genetic Diseases

JEFFERSON CITY — The Missouri Senate gave final approval today (5/4) to <u>House Bill 716</u>, handled by Sen. Rob Mayer, R-Dexter, that would expand newborn screening requirements for certain genetic diseases.

The proposed legislation would establish the *Brady Alan Cunningham Newborn Screening Act* and require the Missouri Department of Health and Senior Services to include screening for certain genetic diseases, including Krabbe, Pompe, Gaucher, Niemann-Pick or Fabry disease. Treatment for these diseases is only effective if it's started before symptoms appear.

The bill is named for Brady Alan Cunningham, an 11-month-old infant from Campbell, MO who died in April from Krabbe, a life-threatening disease that destroys the central nervous system. Former Buffalo Bills quarterback Jim Kelly lost a son to the same disease in 2005 and has played a role in raising awareness of Krabbe and other potentially fatal disorders affecting newborns.

"This legislation would bring earlier diagnosis and intervention for these very serious diseases and give hope to Missouri families," Sen. Mayer said.

The proposed bill also seeks to require the Missouri HealthNet program and the state children's health insurance program (SCHIP) to improve hospital discharge and follow-up care procedures for premature infants born earlier than 37 weeks gestational age. In addition, the Department of Health and Senior Services would be required to prepare written educational materials containing information about possible complications, proper care and support associated with premature newborn infants that would be made available to children's health providers, maternal care providers, hospitals, public health departments and medical organizations.

The bill returns to the Missouri House for a final vote.

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