

State Senator Robert Mayer The Mayer Memo

Senator Robert Mayer - Serving Butler, Dunklin, New Madrid, Pemiscot, Ripley, Stoddard & Wayne Counties



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Newborn Screening Expansion Would Save Lives and Give Hope to Missouri Families

A bill that would expand newborn screening to include five rare and life-threatening genetic diseases is advancing in the Missouri General Assembly, and I couldn't be more pleased. [House Bill 716](#), which I advanced successfully in the Senate and appears to be close to a final positive vote in the Missouri House, would establish the Brady Alan Cunningham Newborn Screening Act.

The proposed legislation would add the potentially fatal metabolic disorders of Krabbe, Pompe, Gaucher, Neimann-Pick and Fabry disease to the list of 29 disorders currently included in newborn screening in Missouri. These rare and inherited diseases are among a group of diseases known as "lysosomal storage diseases" affecting mostly children in which a subunit with the body's cells — the lysosome — malfunctions. In some cases, such as Krabbe disease or infantile Pompe disease, the outcome is invariably fatal if treatment is not instituted promptly. In the case of Krabbe disease, treatment is only effective if provided prior to the onset of symptoms.

The expanded newborn screening measure was inspired by and named for Brady Alan Cunningham, an 11-month-old boy 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 and promoting newborn screening requirements for Krabbe and other potentially fatal disorders. Tragically, the lives of these two families and thousands of others could have been much different with an early diagnosis through newborn screening.

Approximately 4 million infants are born annually in the United States, with an estimated 150,000 born with serious birth defects. In Missouri, approximately 80,000 babies are born each year, with minimum of 10 children are born each year in our state with the five metabolic disorders addressed by House Bill 716. Newborn screening is vital for all infants' health and in some cases a family's only hope of identifying and treating a variety of very serious and life-threatening illnesses.

The passage of House Bill 716 would bring hope and help to many Missouri families by facilitating early detection and increasing the chances for effective treatments so that these genetic diseases no longer bring certain and untimely death to those diagnosed.

As always, if you have comments or questions about this week's column or any other

matter involving state government, please do not hesitate to contact me. You can reach my office by phone at 1-877-291-5584.

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Capitol Office		Website:	Phone Number:
State Capitol Building		http://www.senate.mo.gov/mayer	877.291-5584
Room 422			Fax:
Jefferson City, MO 65101			573.526.1384