

January 24, 2013

Senator Kathy Campbell  
Health and Human Services Committee  
P.O. Box 94604  
Lincoln, NE 68509-4604

RE: LB 225

Dear Senator Campbell and members of the Health and Human Services Committee:

I am writing regarding LB 225 which would require screening all newborns for critical congenital heart disease (CCHD).

I would like to provide several observations of the bill as currently written:

- In Section 5, subsection (2), the meaning and intent is implicit but not explicit that the data reported to the Department is for the "sole purpose of monitoring the effectiveness of the screening mechanism." Monitoring effectiveness implies oversight and quality assurance. Language of "assuring the effectiveness" would imply a more active role in terms of ensuring follow-up diagnosis, referral, and treatment. This distinction of whether or not the bill intends to hold the Department responsible for follow up has fiscal implications. If the intent is for the Department to assure the effectiveness of the screening, which would require follow up, it would require an additional full time equivalent position in addition to the Department's fiscal note, as well as a more extensive data reporting system.
- According to Section 3, subsection (3), a birthing facility means a hospital or other health care facility that provides birthing and newborn care services. Section 5, subsection (2) requires a mechanism for only hospitals to report to DHHS. This requirement is not for all birthing facilities or the person registering the birth (for out of hospital births) who according to the bill, are responsible for obtaining the screening.
- In order to develop standards to be determined in rules and regulations that will be functional in medical practice, the statute should define the role of the newborn's physician or health care provider, specifically in ordering, interpreting and following up on the test. Language similar to the metabolic screening law (shall collect or cause the collection of) could be used, such as "the newborn's attending physician shall test or cause the testing of." Along these lines, there are concerns with the bill in Section 4,

subsection (2) (a) (b) relative to who is responsible, how they accomplish the testing and to whom results are reported. The person registering the birth would still need a physician to order and interpret the test.

Thank you for your consideration of these points. I appreciate the opportunity to provide this information.

Sincerely,

A handwritten signature in black ink, appearing to read 'Joann Schaefer', with a stylized, cursive script.

Joann Schaefer, MD  
Chief Medical Officer – State of Nebraska  
Director, Division of Public Health  
Department of Health and Human Services

cc: Sen. Jim Smith