

**The Senate Public Health and Welfare Committee
Committee Assistant Donola Fairbanks**

Written Testimony of Lin Fennell RN in support of Newborn Screening Act SB364

February 20th 2020

Good Morning,

Thank you for taking the time to read my written testimony. Unfortunately, I am unable to attend this meeting in person as I am currently out of the country, but the Newborn Screening topic is particularly close to my heart.

I am a Registered Nurse with over 40 years' experience caring for the maternal child population across three continents throughout my career. I have educated families and taken blood for newborn screening tests for decades. My most recent passion has involved the discussion of adding SMA to the newborn screening panel, which began at the Kansas Newborn Screening Committee in October 2017 with follow up in May 2018.

I was delighted when the committee agreed to start the lengthy process of adding SMA to the newborn screening blood spot test, which was finalized on Feb 1st 2020. Now I'm not quite sure if funding is no longer available to sustain this test and it's going to have to be withdrawn, OR by adding this test it has eliminated the funding for other important screening tests that have been added to the RUSP. Either way it is imperative that we screen newborns for these illnesses, so treatment options and interventions can be implemented as soon as possible.

In the case of infants with SMA it's a matter of hours/days that make the difference in how much the neuromuscular network is affected. In layman's terms this varies from; Will my child hold his/her head up independently? Will my child eat, swallow and breath independently? Will my child need nutritional and breathing support? Will my child roll over, walk, talk? Will my child die? Yes, these children die at an alarming rate if treatment is not implemented. If a diagnosis is not obtained early in infancy, the muscles fail to work correctly which is impossible to reverse. Muscle degeneration can however be halted but a speedy diagnosis is imperative.

I do hope sufficient funding can be added to the Newborn Screening program so that the Newborn Screening Committee, the KDHE and the laboratory staff can implement nationally recommended screening in a timely manner.

Thank you for your consideration in this very important matter.

Lin Fennell RN State of Kansas

'A voice for those who cannot speak'