February 28, 2022

RE: SB 155 – "Expanding newborn screening services and increasing transfers of moneys to the Kansas newborn screening fund."

To: Senate Committee on Public Health and Welfare

Dear Chairman Hilderbrand and Committee Members,

Thank you for the opportunity to present written testimony in support of SB 155, which concerns the Kansas Newborn Screening Program. I am writing you as a board-certified metabolic genetics specialist who takes care of infants, children and adults from Kansas with the treatable metabolic genetic diseases that make up nearly half of the newborn screening panel. I am also a Kansan who serves as the Chair of the Kansas Newborn Screening Advisory Council, which was established to advise the Secretary of the Department of Health and Environment regarding newborn screening.

I've seen firsthand the profound difference newborn screening has made for my patients. We care for over 200 people in our clinic who have PKU (phenylketonuria), a disease that causes irreversible brain damage if not identified and treated early. I follow several adults in their late 50s and 60s who were born prior to newborn screening. Most of them have significant intellectual disability and live in supervised group home settings. In contrast, those born in 1965 or later, who had newborn screening and thus were identified and started treatment in the first week of life, are not that different from their peers. They've graduated high school, many are working and raising families. I can't emphasize enough how valuable and life altering screening for even this one disease has been for so many.

The Kansas Health and Environmental Laboratories' newborn screening lab and the KDHE newborn screening follow-up program have together maintained a high-quality program even as the newborn screening panel has grown to meet the recommendations of the US Department of Health and Human Services Recommended Uniform Screening Panel, a list of 35 diseases that every state should consider screening for. Since K.S.A. 65-180 was amended to establish a cap on the monies allocated to the newborn screening program in 2017, Kansas has added screening for four additional diseases despite nearly exhausting the allocated moneys in the years prior to the establishment of the cap. These four DHS-recommended diseases bring the Kansas panel to 34, and the program is exploring adding screening for the 35th. Without early identification and treatment, some of these diseases shorten lives, with the most severely affected dying before their 2nd birthday. Newborn screening has changed that dramatically, giving hope to the families of infants born with these diseases. The Kansas newborn screening program would benefit from an increase in the cap on funds so that it can continue to provide screening in a timely manner, provide education for primary care providers who care for these children and consider adding this 35th disease to the panel.

I want to mention that I find the use of the word "expansion" in the short title of this bill somewhat confusing. This bill does not propose adding diseases without thoughtful consideration. In my experience, KDHE and KHEL have, with input from the Newborn Screening Advisory Council and concerned Kansans, judiciously, and with consideration of the benefit and cost to Kansans, added these diseases to the newborn screening panel.

Given that it is imperative to continue to support the Kansas newborn screening program so that it may provide the highest quality and timely services, I urge the committee to support SB 155. Thank you for

reading my testimony and for your continued commitment to the health of newborns and of all Kansans.

Respectfully,

Jennifer Gannon, MD
Clinical Biochemical Geneticist, Children's Mercy Hospital
Chair, Kansas Newborn Screening Advisory Council