

State Representative Ann Meyer, Chair
Iowa Human Resources Committee
Iowa House of Representatives
1007 E. Grand Ave.
Des Moines, Iowa 50319

Dear Representative Meyer and esteemed members of the Human Resources Committee,

Greetings. My name is Carol Cross. My family and I live in Cedar Rapids. I serve as a parent advocate on the Iowa Developmental Disabilities Council as well as on the Congenital and Inherited Disorders Advisory Committee. I am the founder of Iowa Krabbe Network – a coalition of families and friends of individuals diagnosed with Krabbe Disease. I am the mother of two children born with Krabbe Disease and am an active parent advocate in the rare disease community. I am grateful for the opportunity, as a parent advocate, to submit written testimony in support of HSB 690.

HSB 690 ensures that the newborn screening program in Iowa will add the core disorders on the federal Recommended Universal Screening Panel (RUSP) in a timely manner. The disorders on the RUSP have been carefully evaluated and approved by the Advisory Committee on Heritable Disorders in Newborns and Children. Currently, Iowa screens for 32 out of the 35 core disorders on the RUSP.

The RUSP disorders all need early detection to ensure the opportunity for effective treatment. Delayed addition to the panel can mean a baby's diagnosis comes too late for effective treatment. Consider the situation where your child or grandchild is born with a life-threatening disorder that has an effective treatment available. Yet your child or grandchild is not diagnosed with this disorder because it's not included in your state's newborn screening panel. Months pass before your baby is diagnosed. By the time diagnosis is made, the treatment available will not be effective for your baby.

My family's story illustrates well the importance of early detection for life-threatening, treatable diseases. My first child, Joshua, seemed healthy until he was 7 months old. Over the course of a month, he lost the ability to voluntarily move and cried constantly. When he was 8 months old he was diagnosed with Globoid Cell Leukodystrophy (Krabbe disease) and we were told to take him home and try to make him comfortable. There was no treatment to help him because the disease was far advanced. He lived for two more years, suffering from the cruel effects of Krabbe disease. Years later when I was pregnant with our daughter, Laura, we knew to have her tested for Krabbe disease because of Joshua's diagnosis. While I was still pregnant, we learned that Laura had Krabbe disease. Because of her early diagnosis, she was able to receive a bone marrow transplant when she was just 19 days old. This year we will celebrate her 23rd birthday. Early diagnosis gave Laura the chance for a happy, fulfilling life – a chance that Joshua never received. Krabbe disease is not currently on the RUSP but the submission for its nomination was made in July of 2021 and we are hopeful that Krabbe Disease will be added to the RUSP in the near future. While Krabbe is not yet on the RUSP, 10 states do screen for it including our neighbors, Missouri and Illinois.

Krabbe Disease, like the disorders on the RUSP, needs an early diagnosis so that effective treatment can be given. Without early diagnosis, the disease progresses too far for the treatment to significantly improve the quality of life for the individual.

HSB 690 is vital to the wellbeing of all Iowans. HSB 690 assures an updated newborn screening program in our state. Please join your fellow colleagues, within your own party and across the aisle, to make a difference for every baby born in Iowa. Iowa's Newborn Screening program needs to be updated. Please support HSB 690, to ensure the timely addition of life-threatening, treatable conditions to the newborn screening panel - giving every baby born in Iowa the opportunity for a healthy start and a happy life.

Thank you,

Carol Cross,
Parent Advocate
Iowa Krabbe Network