

Comment Report

Health and Human Services

Date: 02/15/2022

Time: 09:00 AM

Location: RM 103, Sup. Ct. Chamber

Name: CAROL CROSS

Comment: 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 writing now 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. 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. Please support HSB 690 to update our Newborn Screening Program and give all babies born in Iowa a healthy start and opportunity for effective treatment of lifethreatening disorders.