Dear Esteemed Colleagues of the Iowa State House:

My name is Doug Passow and I am here to address you as the CEO/President of the Gene Giraffe Project, which is located in Clare, northwest of Fort Dodge, and as an uncle to a niece and a nephew who were born with a rare disease called GM1 gangliosidosis. I am asking for your support of (HBS 690), the newborn screening bill. This crucial legislation will make certain newborns receive vital early diagnosis and intervention measures by ensuring each condition listed on the Recommended Uniform Screening Panel (RUSP), developed by the Secretary of the United States Department of Health and Human Services and the Advisory Committee on Heritable Disorders of Newborns and Children, is included in Iowa’s Newborn Screening Program within two years of being added to the RUSP. Early diagnosis and intervention has been vital for my family.

In 2009, my brother Danny and his wife Andrea had a baby girl named Ava. The first six months of Ava’s life were lived regularly. After six months, she progressively lost all of her ability to crawl, talk, and even move. She was diagnosed with GM1 about a year into her life. GM1 gangliosidosis is a lysosomal storage disease that progressively attacks the neurons in the brain and spinal cord until death by the age of 2 or 3.  By that time she was diagnosed, the disease had progressed too much to provide much of any treatment other than to do what’s necessary to prolong her life. She died in 2012 due to GM1.

In 2017, my brother Danny and his wife Andrea had another child, a baby boy named Jackson. After Jackson was born, he was genetically tested and found to have the same disease as his sister. At around 45 days old, Jackson was the youngest person in University of Minnesota’s Children’s Hospital to undergo a bone marrow transplant. His BMT was deemed successful as he regained his enzyme he was missing. As you can see, early diagnosis and intervention was vital for my family.

While there is currently no newborn screening for GM1 gangliosidosis, Ava and Jacksons’ story highlights the importance of early diagnosis and treatment. Newborn screening allows for the earliest possible diagnosis and immediate access to potentially life-saving treatments and its timely availability will help to save lives in Iowa.

Thank you for the opportunity to speak today and I ask you to please support HSB 690, so that every Iowa newborn has the opportunity for early diagnosis and treatment.