



State Representative Kristin Boggs
State Representative Jim Butler

Sponsor Testimony – House Bill 397

Chairman Huffman, Vice Chair Gavarone, and Ranking Member Antonio, thank you for the opportunity to testify today on House Bill 397. The goal of this legislation is to require that all newborns to be screened for Spinal Muscular Atrophy (SMA). SMA is the leading genetic cause of death in infants today, affecting approximately 1/11,000 babies. SMA is a neurodegenerative disease that robs infants and toddlers of their ability to walk, swallow, and breathe.

However, there is new hope for treating SMA. On December 23, 2016 the FDA approved the first-ever treatment for SMA. Prior to this newly approved treatment the life expectancy of an infant diagnosed with SMA was typically under 2 years old. But, with this treatment, infants diagnosed with SMA prior to the onset of symptoms have achieved unprecedented motor milestones of sitting, standing, and walking. It is critically important to begin treatment prior to the onset of symptoms because the treatment cannot reverse the damage SMA has already caused. Instead, treatment works to prevent the future degeneration of motor neurons.

This legislation is named in honor of Tiger, a constituent of mine, and Jackie, a constituent of Representative Boggs. Tiger, was born on August 24, 2012. At 5 weeks, Tiger began developing a cough; a few days later he was admitted to the hospital. After being in the hospital 31 days, doctors finally diagnosed Tiger with SMA. Sadly, Tiger passed away when he was 2 months and 20 days old.

Jackie, also diagnosed with SMA as an infant, and she recently celebrated her second birthday. This milestone is incredible because at two-years-old Jackie surpassed her doctor's initial prognosis for her life expectancy! We hope this bill serves to honor the families that have lost loved ones to SMA, and provide hope to families that are currently caring for a loved child with SMA.

Thank you for the opportunity to testify before you today, we are both available for any questions you may have.

