

Testimony of Marybeth Camboni for HB 110

Chair Oelslager, Vice Chair Plummer, Ranking Member Crawley and member of the committee. I am Marybeth Camboni. Since 2017 I have advocated relentlessly to get Spinal Muscular Atrophy (SMA) added to the Newborn Screen in Ohio. SMA is a devastating disease, it is ALS but for infants, affecting 1 in every 10,000 births. At that time SMA was the number one genetic killer of children under two years of age. My daughter, Jacqueline, has this disease. When she was born in 2015, SMA was not screened for in any state. She is lucky she has a very observant mother or she could have been one of over 90 percent of children who die or are permanently ventilated from SMA by the time they reach 2 years of age.

My husband Christopher, my friend Stephanie Noll, our state representative Kristin Boggs and I tried to pass legislation to add SMA to the newborn screen in December 2017 with HB 397. It was shut down by the general assembly. In February 2018 the Ohio Department of Health Advisory Panel voted to add SMA to the newborn screening panel. Since that time there have been around 18 infants identified and saved. We were told that SMA was officially added to the newborn screen, which was untrue. We were told that every child is being screened, which is also untrue. In December 2020 and January of 2021, over 10,000 infants were not screened for SMA, due to supply issues. These infants were not retested because the disease was not officially being added to the newborn screen, over 3 years after it was voted on. This is incredibly frustrating to know that not every baby is being screened when a promise was made to do so.

As with any disease, early detection saves lives. Newborn screening has already saved the lives of countless infants in the United States, including those in Ohio. The fact that it has taken this long and it has not been officially added is an injustice to babies being born in this state. I am in full support of HB 110. Hopefully this will end the loophole of infants not being tested when a promise was made to do so, for SMA and for all other diseases.