

Chairman Huffman, Vice Chairman Gavarone, and Ranking Member Antonio thank you for the opportunity to testify today. My name is Marybeth Camboni. I have worked at Nationwide Children's Hospital for 14 years. I am an SMA Mom to Jackie who is almost 3. My family's story, is quite extraordinary, but is irrelevant today.

In January I started an online petition to get SMA on the newborn screen in Ohio. Almost 19,000 people signed the petition. I will read to you a passage from another SMA mother:

I'm signing this petition because I lost my son to SMA in 2008. He passed all of his newborn screenings with flying colors. He ate, slept, and smiled like a champ. He was a seemingly happy, and healthy newborn. Then after a little concern over arm and leg movement we were referred to a neurologist. At worst I feared he might need some PT, my fear was that he wouldn't be able to play soccer. If only! At 8 weeks old he was diagnosed with SMA. The neurologist quickly pointed out the symptoms of this deadly disease that we had never heard of before... low muscle tone, weak cry, frog legs, belly breathing... it was May 2, 2008. That was the day we were told our beautiful baby would most likely not see his second birthday or not even his first. He died in my arms on August 16, 2008, after spending 35 long, hard days in the PICU, living only 5 months. We would have given anything to save him, but the disease had quickly taken a toll on his precious little body. But 9 years later, NOW there is finally a VIABLE treatment available to ALL patients living with SMA, called Spinraza. The sooner the treatment is given, the better the results. So, I ask you this... Why wouldn't it be mandated to implement newborn screening, for the #1 genetic killer of babies under age 2? If he had born today, he could have been screened right away and ultimately been given a drug that would have saved him from this deadly disease, ravishing his little body. He couldn't be saved and he is missed every single moment of every single day. Please implement this screen, not only for him AND the countless others taken, but for someone else's precious, seemingly healthy newborn baby being born today, tomorrow and all the days after that. This includes Corey born in 2012, in Dayton, who lived only 2 months. For Jade, born in Columbus, in 2014, who lived only 6 months. And for Owen, born in 2016, in Cincinnati, who lived only 3 months. Thank you!