

TESTIMONY OF CHRISTOPHER C. CAMBONI

Chairman Huffman and the members of the committee, thank you for the opportunity to testify today in support of House Bill 397. And my sincerest thanks to Representative Boggs and Representative Butler for sponsoring this bill.

My name is Chris Camboni. My wife, Marybeth, and I have three wonderful daughters. Our youngest, Jackie, was diagnosed with Spinal Muscular Atrophy in June 2015 at just four months of age. Marybeth had noticed that Jackie had low muscle tone and wasn't hitting developmental milestones at the same rate as our other two daughters. Jackie's pediatrician referred us to a genetics counselor and, just a few days later, a simple blood test confirmed our worst fears.

Spinal Muscular Atrophy—or SMA for short—is the number one genetic killer of infants. The disease affects the body's ability to produce motor neurons. This leads to severe muscle weakness. Babies diagnosed before six months of age have an average life expectancy of two years if the disease is untreated. Those children affected by the most severe types of SMA never sit up unaided. Others never walk. Eventually, affected individuals can lose the ability to swallow and to breathe unaided.

Early intervention is key. Although there is no cure, there is a chance to halt the progression of SMA in those affected by it. This past December, the FDA approved the first drug to treat SMA. There are other experimental treatments currently being developed.

But early intervention requires an early diagnosis. Although approximately 1 in 50 people are carriers for the disease, too few people know about it. Until Jackie's diagnosis, my wife and I had no idea we were carriers. Neither of our families have a history of SMA.

Jackie benefitted from a mother who recognized something was not quite right, and from a pediatrician who didn't tell us to give Jackie time to grow out of it. And our family is fortunate to live practically down the street from a children's hospital with doctors, nurses, and staff that know of and can identify SMA.

As a result, Jackie was diagnosed early enough to receive the benefit of early intervention. My little girl—who was never supposed to sit unaided—can push herself in a wheelchair, can stand without braces, and is learning to walk. More importantly, she can feed herself and breathe unaided. And she's smart as a whip and will talk your ear off if given half a chance.

Not every Ohioan is lucky enough to live near a hospital with staff that can identify the symptoms of SMA. But a simple test can identify the disease. Thus, every newborn baby can benefit from the proposed change to Ohio law to require SMA to be added to the panel of conditions screened for at birth.

Jackie turns three next month. She has lived almost a year beyond her life expectancy. Although Jackie won't benefit directly from the bill, it would be a wonderful birthday gift to her—and a gift to all future babies born in Ohio—if you would allow House Bill 397 to move forward.

Thank you again for the opportunity to testify today.