

"Chairman Huffman, Vice Chairman Gavarone, and Ranking Member Antonio thank you for the opportunity to submit my testimony in support of SMA newborn screening.

My name is Madison Rose Reed. I am 20 years old and have SMA type 1. I was born on February 4, 1997. I came into this world like any other child-screaming and kicking, pink and rosy. I was a very special little girl. My parents Annette and Carl just didn't know yet just how special I would be.

Beginning around four months of age, my parents noticed that I was having difficulty accomplishing normal physical developmental skills. I couldn't hold my head up and wasn't rolling over. My pediatrician just thought I was a lazy girl. I kept moving less and less and still had more trouble holding my head up. I began having trouble swallowing and developed my very first of many aspiration pneumonia's. After switching pediatricians and finally seeing a specialist in developmental disabilities, at Nationwide Childrens Hospital I was diagnosed with Spinal Muscular Atrophy (SMA) type 1 at 8 months old. My parents were told to take me home and make me comfortable. The doctor who diagnosed me told my parents there was no cure and they did not see Type 1 children in any of the clinics at Nationwide. My parents we're sent out the door with nothing except a death sentence for me.

I was diagnosed with the most severe and life-threatening form of this disease, Type 1, also known as Werdnig-Hoffman disease. My parents contacted the MDA clinic and were initially told they could see me in 6 months. My mom told them I might not live that long according to the doctor at Nationwide. Dr. Jerry Mendell saw me within a few weeks but there was still no treatment or cure. He told my parents to find a good pediatrician which they did. Based upon this original diagnosis, I was not expected to live past the age of two. As my parents learned more and more about this disease on their own, they learned that my chance of survival was much better than the original diagnosis. We traveled to Newark, New Jersey, to visit a pulmonary specialist in the area of SMA. Dr. John Bach. He gave my parents real hope that I could live a comfortable, happy life well beyond the age of two. With the use of his noninvasive respiratory protocol for SMA which includes the use of bipap and cough assist along with an amino acid diet, I have been able to live 20 years and I am still enjoying a happy life! I was lucky to have parents and a pediatrician who didn't take no for an answer and who were willing to try everything possible. Today there are type 1 babies getting the same diagnosis and being told there is nothing that can be done. There is no time to wait. Every second counts and can make a difference in life or death. Type 1 babies do not have time to wait. Newborn screening can change that and give every child with SMA a real chance at life and access to a treatment and cure!

A year and a half after I was diagnosed my family joined forces with other families in Ohio to support research for SMA and to develop a clinic at the Ohio State University/Nationwide Children's Hospital dedicated to SMA. OSU led the way in blood testing to diagnose SMA. In addition, OSU developed SMA mice and other animal models. They have proven that by replacing the missing SMN1 gene using gene replacement therapy SMA can be corrected/cured. Also by increasing the SMN2 back up gene with an ASO like the now FDA approved drug Spinraza, SMA can be treated. Both of these drugs need to be given as early as possible however

to be the most effective. Newborn screening can make that possible and prevent damage and even death. Further drug testing and development research is currently being done on these mice as well as other animal models to find other safe and effective treatments for SMA.

My highest priority would be to save the lives of all SMA children and adults. SMA newborn screening could help me do this. Beyond that I am committed to making this disease easier for other families to deal with. I try to give families hope by sharing my experience with this disease through social media. I've dedicated my life to raising funds and awareness for SMA. The SMA Awareness Ribbon created by my aunt in 1997 was inspired by me. It holds the true meaning of our fight to cure SMA... pure, innocent, inner strength, courage and love!

Even though I have SMA, I still love to do things that any other 20 year old loves to do like shop, go places like the movies, concerts, the zoo and most of all Walt Disney World! Every life deserves that chance to live and enjoy life! You hold that life and chance in your hands right now.

Throughout my battle with SMA, doctors in central Ohio knew few strategies to deal with the impact of this disease. Through much struggle and countless sleepless nights, my parents and I have learned so much but much more needs to be learned by so many. SMA being added to the Newborn Screening opens up a whole new way to educate every doctor in Ohio and save So Many Angels!

Please vote YES to House Bill 397, to screen newborns in Ohio for SMA.

Thank you for your time and consideration!
Madison Reed



I
LIVE
with
SMA!

I love



Believe In Miracles! Never stop believing!

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