Chairman Burke, Vice Chair Huffman and Ranking Member Antonio and members of the Committee....

Thank you for having us here to speak on behalf of the bill proposed to make September Hirschsprung’s Disease Awareness Month.

My name is Heidi DiVincenzo and I am the proud mother of a warrior girl that has Hirsprung’s Disease. On April 28,2005 my husband and I gave birth to our third child, a healthy baby girl. 2 days later the health of that little baby was on the line as metro trauma life flight team came to take her to Cleveland clinic children’s hospital.
We asked the trauma team if they were able to get her stable enough to go via ambulance so if she would pass away, she would be with one of us. We arrive via ambulance at CCF children, she was taken directly to surgery, we were told 3 things could be wrong, with 2 of those options she would die, and with one, Hirschsprung's Disease, she would live. We went to the chapel with our entire family and we prayed. We prayed for Hirschsprung's Disease and luckily, that’s what we got. 6 hours later our baby was out of surgery, we learned her intestines had ruptured, she had a colostomy bag but she was stable and she was alive. It was then that we started learning about this disease she was diagnosed with that we could barely even pronounce.

Hirschsprung’s disease (I’ll refer to it as HD) is is a congenital abnormality where the nerves and ganglion cells within the colon do not develop properly. This area without ganglion cells can range from a small section to the entire colon even extending into the small intestine. The lack of ganglion cells prevents normal passage of stool through the affected portion of the colon. It occurs 1 out of every 5,000 male births and 1 out of every 25,000 female births.

Research on the internet and from some experts say that the first sign of Hirschsprung's Disease is not passing meconium (or poop). Our daughter did poop. We never knew she was sick. We never knew anything was wrong. She ate. She slept. She barely cried...and she pooped. This lack of information for doctors and families almost led to the death of our child.

The information we found also showed that after the first 1-2 surgeries for HD, children go on to have a normal life. This again, couldn’t be farther from the truth. Lizzie has had 6 surgeries; 1 at 2 days old, 1 at 10 months old, 1 at 1 year, 1 at 5 years old, 1 at 13 years old and one this year at 14 years old (and one more coming up in her adult years). These surgeries have ranged any where from 2 hours to 8 hours long. She has been hospitalized for dehydration and enterocolitis (a life threatening side effect of HD) at least a dozen times, had numerous colonoscopies, barium x-rays, regular X-ray, anal mammography, more IV’s than I can even count and even more tests or prodding that I can’t remember or are too personal to list. Just lack week after having the flu for only a 2 hour period she got so dehydrated that she passed out in our home and was brought to Nationwide Children’s via ambulance. None of these are examples of a normal life, as articles and some experts have said.

These are the reasons why we feel more awareness is needed when it comes to this disease....and there are thousands and more stories that are similar. Deaths from misdiagnosis. Children suffering because we just do not know enough. Pooping diseases aren’t pretty. They just aren’t. But to live we have to poop. Period. By considering to make September Hirschsprung's Disease Awareness month you will help us get one step closer to more awareness; for doctors, nurses, EMS teams, parents and families. We would be following The country of Australia and the state of Pennsylvania. Our goal is nationwide, even worldwide, awareness and I am honored to be a part of trying to make that happen.

Our family would greatly appreciate your consideration and acceptance of this bill.

Thank you so much for your time.