

Chairman Burke, Vice Chair Beagle, Ranking Member Tavares, and members of the Ohio Senate Health, Human Services, and Medicaid Committee, thank you for the opportunity to submit my written testimony. My name is Danielle Spears and I am testifying as a proponent to S.B. 23.

We went to our OB office on December 27<sup>th</sup>, 2013 at 16 weeks gestation to find out the sex of our baby. We left the office with a diagnosis that we could not pronounce and a request to *not* look up images on the internet. The diagnosis was called an omphalocele. Our doctor quickly referred us to the Fetal Care Center in Cincinnati, Ohio to obtain more testing which included an amniocentesis, two fetal MRIs and a fetal echocardiogram. These tests revealed that our daughter Zoë had a *giant* omphalocele. An omphalocele is a type of abdominal wall defect in which the intestines, liver, and occasionally other organs remain outside of the abdomen in a sac because of a defect in the development of the muscles of the abdominal wall. Zoë's omphalocele contained the majority of her liver, a portion of her stomach, her gallbladder and some of her intestines. Tests also revealed that her lungs were smaller than normal and that she had a small heart defect. Genetic testing came back negative for any genetic disorders.

This was a lot of information for our family to take in. We did not know anyone affected by this diagnosis nor did we know what we would be up against. Dr. Foong Yen Lim and the amazing doctors working with the Fetal Care Center at Cincinnati Children's Hospital Medical Center did their best to answer all of our questions but overall there was so much left unknown. Zoë's long term outcome depended on the severity of her omphalocele which could not be determined until she was born.

Our daughter spent her first 11 weeks of life in the NICU. Her first surgery stretched her skin over her omphalocele when she was 3 weeks old. Her last surgery placed her organs *inside* her abdomen with a muscle closure when she was 11 months old. Today, Zoë is a very energetic, loving and resilient two-year-old with a personality like no other. She still battles with reflux and slow weight gain but overall she is a typical little girl in her terrible twos!

Senate Bill 23 would create Omphalocele Awareness Day in Ohio. Bringing awareness to this birth defect will allow future and existing families to know that they are not alone. I remember feeling overwhelmed, alone and scared. I would ask myself "How can Zoë survive this?" Sometimes giving up hope. When you are faced with the unknown, people tend to focus on negative outcomes more, which was the case for me. I did not imagine it was possible to have a little girl that is developmentally on target and thriving like she is today.

The support group "Mothers of Omphaloceles" and also support from Children's Hospital helped us overcome our feelings of helplessness and confusion. Members of "Mothers of Omphaloceles" have been raising awareness and sharing their experiences since their founding in 1999. Public awareness, expert medical care, accurate and early diagnosis, and social support systems are all essential for optimal treatment and this is what we hope to gain with Senate Bill 23. This platform will give hope, support, and education to many families affected by an omphalocele.

I would like to thank Senator Terhar for introducing this essential piece of legislation and supporting January 31<sup>st</sup> as Omphalocele Awareness Day. I sincerely appreciate the Committee's time and consideration of Senate Bill 23.