Proponent Testimony of Foong-Yen Lim, MD
Senate Bill 23
Before the Health, Human Services, and Medicaid Committee.
February 17, 2017

Chairman Burke, Vice-Chair Beagle, Ranking Member Tavares and members of the Senate Health, Human Services and Medicaid Committee; thank you for allowing me to submit my testimony as a proponent to Senate Bill 23. My name is Foong-Yen Lim. I am a pediatric and fetal surgeon at Cincinnati Children's Hospital. I have been caring for patients with omphalocele for more than 15 years.

Babies with omphalocele have a hole in their belly with absence of abdominal muscles and skin. The spectrum of severity can vary from a small hernia to a large defect with extrusion of the liver, the guts, and sometimes the heart and the pelvic organs. Normally, at 3-4 weeks of gestation, the body of a fetus starts to fold up to form the various compartments of the body. When this infolding process goes wrong in a developing fetus, omphalocele occurs. The diagnosis of an omphalocele can be made as early as 10 to 12 weeks of gestation by prenatal ultrasound. The incidence of omphalocele is reported between 1 in 300 to 4000 fetuses. These pregnancies are affected by preterm labor in 26-65% and intrauterine growth restriction in 6-35%. There is also a high rate of emergency cesarean delivery due to fetal distress.

Besides an abdominal wall defect, babies with omphalocele can have additional problem, ranging from minor, nonlethal abnormalities to multiple complex life-threatening abnormalities. Associated malformations and anomalies can accompany omphalocele in 50%-75% of cases, and chromosomal abnormalities can be seen in 30-56%. Cardiac anomalies are the most common (19-32%), other systems involved were skeletal, gastrointestinal, genitourinary and central nervous. Sadly, many of the fetuses with multiple anomalies died before birth or during the immediate perinatal period. As a result, the incidence of omphalocele seems lower at 1 in 4000-7000 livebirths.

Babies with omphalocele can have impaired lung growth. Thus, they may develop breathing difficulty after birth requiring mechanical ventilation and sometimes tracheostomy for the first few years of their life. Respiratory complications account for a significant percentage of the morbidity and mortality. Rupture of omphalocele membrane can significantly worsen the prognosis. Besides increasing the risk of liver injury with hemorrhage, there is an increased risk of peritonitis and sepsis with elevated risk of morbidity and mortality. It is also common for these babies to have feeding difficulties and severe gastroesophageal reflux. They may need total parenteral nutrition and feeding tubes. Most babies require multiple surgical interventions under general anesthesia before all of the abdominal contents can be internalized and the abdominal wall defect closed. In fact, in 2006, Lakasing et al. from King's College Hospital reported that fewer than 10% of the patients diagnosed prenatally with omphalocele survived to surgical repair. Most babies also required prolonged hospitalization and frequent follow up visitations in clinic to monitor their growth and development. They also require early intervention as they are at risk of developmental delays. In summary, omphalocele is not just a hole in the belly but a birth defect with increased risk of associated anomalies as well as significant morbidity and mortality. Although we have seen improvement in the outcomes of these patients in the recent years, more need to be done to understand omphalocele better so we can decrease the morbidity and mortality related to this condition further.

Thank you for your time and consideration. I sincerely appreciate Senator Lou Terhar and Representative Terry Johnson and their staff for all of their efforts in supporting this legislation to designate January 31 as "Omphalocele Awareness Day" to raise public awareness and encourage medical research on this birth defect.