**Senator Lou Terhar**
**8th Senate District**

# Senate Bill 23 Sponsor Testimony

Senate Health, Human Services and Medicaid Committee
February 14, 2017

Chairman Burke, Vice Chair Beagle, Ranking Member Tavares, and members of the Health, Human Services, and Medicaid Committee, thank you for allowing me the opportunity to testify today on behalf of Senate Bill 23.

This legislation will designate January 31st as Omphalocele (om•pha•lo•cele) Awareness Day. Prior to a constituent reaching out regarding Omphalocele Awareness, I had never heard of the rare birth defect. An omphalocele is an abdominal wall defect that occurs when an infant's intestines, liver, and occasionally other organs grow outside of the body and push through into the navel. The organs are covered in a thin, nearly transparent sac and almost always require surgery to correct. The omphalocele can be small, with only a small loop of intestines present outside the abdomen, or large, containing most of the abdominal organs.

Sometime between the 6th and the 10th weeks of pregnancy, the intestines project into the umbilical cord as they are growing. By the 11th week of development, the intestines should return to the abdomen. When the baby is growing and developing during pregnancy, there is a small opening in the abdominal muscles for the umbilical cord. As the fetus matures, the abdominal muscles should meet in the middle and grow together, closing off this opening. An omphalocele occurs when the abdominal organs do not return to the abdominal cavity as they should.

A small type omphalocele, involving protrusion of a small portion of the intestine only, occurs in one out of every 5,000 live births. A large type omphalocele, involving

protrusion of the intestines, liver, and other organs, occurs in one out of every 10,000 live births.

Approximately 25-40% of babies born with an omphalocele also experience other abnormalities and difficulties that they must live with for life. Thirty percent have a chromosomal abnormality, most commonly Trisomy 13, Trisomy 18, Trisomy 21, Turner syndrome, or triploidy. More than half of babies with omphalocele have abnormalities of other organs or body parts, most commonly the spine, digestive system, heart, urinary system, and limbs.

The diagnosis of an omphalocele may take place during an ultrasound while the mother is still pregnant. A recent study found that 75% of omphaloceles were diagnosed by ultrasound, most commonly between weeks 12 to 18 of pregnancy. When there are no other birth defects present, an omphalocele is not believed to be hereditary and the chances for another affected pregnancy are small. If the omphalocele is part of a genetic syndrome, the chances for another affected baby could be as high as 50%, depending on the condition.

Initial treatment for an omphalocele depends on how severe the condition is and whether there are any other associated conditions that take priority. If the baby has no additional conditions, treatment for the omphalocele may begin right away. If the baby also has a cardiac defect or poor lung development, these conditions may be addressed before the omphalocele. The baby's heart and lungs will need to be stabilized before any surgical treatment for the omphalocele can be attempted.

As we raise awareness, we are encouraged that there will be more support for research to help treat this rare birth defect and provide resources and support to families faced with this diagnosis. Chairman Burke, I thank you once again for the opportunity to come before you today on behalf of Senate Bill 23. If there are any questions, I would be happy to answer them at this time.