

House Bill 108 Sponsor Testimony House Health Committee 10/15/19

Chairman Lipps, Vice-Chair Manning, Ranking Member West, and distinguished members of the House Health Committee, thank you for the opportunity to offer sponsor testimony on House Bill 108, which would designate June 30th as Arthrogryposis Multiplex Congenita Awareness Day.

Arthrogryposis Multiplex Congenita (AMC), is a condition in some newborns which results in the decreased flexibility of joints and strength of muscles. If not treated immediately with therapy, this condition can cause further physical impediments. There is no cure for AMC; however, with physical therapy and other treatments, improvement of some motor functions can be regained, and the affected individual can go on to lead a productive and independent life. The condition currently affects approximately every 1 in 3,000 live births, and is known to affect both males and females equally. It has been found that 20 to 30 percent of newborns with AMC will die within the critical period just after birth, as they likely will have a major debilitation in their central nervous system. The cause of AMC depends upon the type that it is. Today, there are more than four hundred variations of AMC, and even more unidentified. The cause for many types is still unknown, as AMC is not a specific diagnosis but a physical finding that can be associated with a number of different disorders.

Engaging in a full-blown discussion about Arthrogryposis Multiplex Congenita, with rich and meaningful input from all corners, will support the affected individuals and their families. It is critically important to first raise awareness, which HB 108 seeks to accomplish.

Thank you again for the opportunity to testify on behalf of HB 108. I would be glad to answer any questions you may have.