



**State Senator Stephanie Kunze  
16th Ohio Senate District**

*Senator Stephanie Kunze  
Senate Bill 275  
September 1, 2020  
Senate Health, Human Services and Medicaid Committee  
Sponsor Testimony*

Chairman Burke, Vice Chair Huffman, Ranking Member Antonio, and members of the Senate Health, Human Services and Medicaid Committee. Thank you for allowing me to present sponsor testimony on Senate Bill 275.

Senate Bill 275 would designate November 16th as Sanfilippo Syndrome Awareness Day, bringing attention to a rare genetic condition that affects 1 in 70,000 children. First described in 1963 by Dr. Sylvester Sanfilippo, Sanfilippo Syndrome, scientifically known as Mucopolysaccharidosis type III (MPS III), is a disease in which the body is missing or does not have enough enzymes needed to break down long chains of sugar molecules. As a result, the molecules build up in different parts of the body and cause various health problems. Sanfilippo Syndrome is a metabolic disorder that causes numerous health ailments for the children who live with it.

Sanfilippo Syndrome affects mostly the brain and is one of a group of conditions called 'childhood dementia'. Over time, brain cells fill up with waste that the body is unable to process. As the disease progresses, the brain experiences damage, and the central nervous system begins to shut down. Children over time will experience severe hyperactivity, disordered sleep, loss of speech, intellectual disability, cardiac issues, seizures, loss of mobility, and finally death, usually before adulthood. Unfortunately, there is currently no treatment or cure available. However, researchers around the world are working hard to develop effective treatments. Several types of treatments, such as gene therapy, are currently undergoing clinical trials. Although steps are being taken to eradicate this disease, there is still much work to be done to find cures and raise the general public's awareness.

The Cure Sanfilippo Foundation established World Sanfilippo Awareness Day to spread awareness and spark conversations about Sanfilippo Syndrome, all while honoring the children currently living with the disease and those who have passed away. The first iteration of this day was celebrated on November 16th, 2019. I hope to see the State of Ohio and Ohioans recognize Sanfilippo Awareness Day this November 16th, signaling our support for the children and families around the world fighting this disease as well as the researchers and scientists developing treatments and cures.

Chairman Burke and members of the Senate Health, Human Services and Medicaid Committee, thank you again for allowing me to present sponsor testimony on Senate Bill 275. I would be happy to answer any questions that the committee might have.