HOUSE OF REPRESENTATIVES
COMPILATION OF PUBLIC COMMENTS

Submitted to the Committee on Human Services

For HB 2641

Compiled on: Tuesday, March 21, 2023 2:46 PM

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Hearing Date: March 21, 2023 8:00 AM

Susan Burek

Texas Parent to Parent, Protect Texas Fragile Kids, Loving Hearts for All

nacogdoches, TX

Thank you for allowing me to testify regarding HB 2641. My name is Sue Burek and I live in Austin, Texas. I'm a parent, an advocate for people with disabilities, and a member of several advocacy organizations that serve families with children with disabilities, including Texas Parent to Parent, Protect Texas Fragile Kids, and Loving Hearts for All.

I am testifying IN SUPPORT OF HB 2641, which allows the Medicaid to cover and reimburse claims for the provision of rapid whole genome sequencing to certain infants with acute or complex illnesses. Many infants have hard to diagnose illnesses, and whole genome sequencing may be the only way to identify and treat their disorder. This is a medically appropriate and humane way to provide appropriate diagnosis and treatment services to these infants with acute or complex illnesses that are otherwise difficult or impossible to identify. The cost of the whole genome sequencing, while expensive, will be lower than the cost of misdiagnosis and mistreatment of the infant's illness, especially when errors or delays in the accurate diagnosis and treatment of the condition could lead to months or years of inappropriate treatment which could lead to an unnecessary and avoidable exacerbation of the illness or even lead to the untimely and avoidable death of the infant.

About 10 years ago, after many years of wild goose chases by doctors who were desperately trying to diagnose and treat my daughter's mysterious medical condition, she was finally approved for whole genome testing. The results of her whole genome testing finally provided clear and simple answers to the mystery about her medical condition, which allowed her doctors to finally begin to provide appropriate medical treatment for her condition.

Before her whole genome testing was approved, her doctors had conducted many exploratory and expensive tests over the years in a valiant effort to identify and treat her condition. In retrospect, the cost of whole genome testing would have been less than the cost of the many exploratory and expensive tests that were conducted prior to her whole genome testing. If she had gotten earlier access to whole genome testing, it would have opened the door to appropriate medical treatment for her condition, which was delayed by about 10 years, which would have saved a significant amount of avoidable medical costs incurred by us and reimbursed by our insurance company for medical treatments that were ordered by her doctors, but which failed.

Please vote to APPROVE HB 2641. Thank you very much for your consideration of my request.