



STATE of MINNESOTA

Proclamation

- WHEREAS: Wiedeman-Steiner Syndrome is a rare genetic disorder which can cause developmental delay, feeding challenges, short stature, and low muscle tone; and
- WHEREAS: The syndrome was originally described in 1989 by Hans-Rudolf Wiedemann. The genetic basis for the syndrome was identified by Dr. Wendy D. Jones in 2012; and
- WHEREAS: Medical researchers with WSS project that there are only a few hundred patients worldwide; and
- WHEREAS: There are at least eight people living with Wiedemann-Steiner Syndrome in the state of Minnesota; and
- WHEREAS: Wiedeman-Steiner Syndrome is a rare syndrome with low awareness. While the estimated number of individuals affected by WSS is seemingly low, the actual incidence of WSS may be greater than present estimates due to misdiagnosis and/or lack of awareness; and
- WHEREAS: Diagnosis may be difficult and expensive leading WSS patients to be given other, incorrect medical explanations or a less specific and broader diagnoses like autism; and
- WHEREAS: Once a person reaches a certain age or phase in their lifetime having been mis-diagnosed or gone undiagnosed, they may stop looking for answers to their symptoms and never receive an appropriate diagnosis or treatment; and
- WHEREAS: Those affected with Wiedemann-Steiner Syndrome and their families may benefit from interventions including physical, occupational, speech, feeding, and/or behavioral therapies; hippotherapy and music therapy; and individualized special education.

NOW, THEREFORE, I, TIM WALZ, Governor of Minnesota, do hereby proclaim Sunday, September 15, 2019, as:

WIEDEMANN-STEINER SYNDROME AWARENESS DAY

in the State of Minnesota.



IN WITNESS WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Minnesota to be affixed at the State Capitol this 13th day of September.

GOVERNOR

SECRETARY OF STATE