



Proclamation

WHEREAS, Phelan-McDermid Syndrome, also known as 22q13 Deletion Syndrome, is a rare genetic condition caused by a mutation of the SHANK3 gene or a deletion of genetic material; and

WHEREAS, the most common characteristics found in patients with Phelan-McDermid Syndrome are intellectual disability of varying degrees, delayed or absent speech, symptoms of autism spectrum disorder, low muscle tone, motor delays, and epilepsy; and

WHEREAS, symptoms such as weak muscle tone and developmental delay usually surface in very early childhood, sometimes at birth and within the first six months of life; and

WHEREAS, affected individuals tend to have a decreased sensitivity to pain, reduced ability to sweat, leading to greater risk of overheating and dehydration; and

WHEREAS, this microdeletion is rarely uncovered by typical genetic screening, therefore a fluorescence in situ hybridization, or FISH test, or whole exome sequencing (WES) is recommended to confirm the diagnosis; and

WHEREAS, there is currently no cure nor treatment, but researchers are working hard to improve our knowledge of Phelan-McDermid Syndrome and develop drugs and therapies for treatment; and

WHEREAS, the Phelan-McDermid Syndrome Foundation serves to improve the quality of life, provide family support, accelerate research and raise awareness through scientific educational opportunities and informational exchange;

THEREFORE I, DAVID Y. IGE, Governor, and I, DOUGLAS S. CHIN, Lieutenant Governor of the State of Hawai'i, do hereby proclaim October 22, 2018 as

“PHELAN-McDERMID SYNDROME AWARENESS DAY”

in Hawai'i and ask the people of the Aloha State to join us in raising awareness of this rare genetic condition and provide emotional support to families going through the unique challenges that a rare disease poses every day.

Done at the State Capitol, in Executive Chambers, Honolulu, State of Hawai'i, this fourth day of September 2018.

DAVID Y. IGE
Governor, State of Hawai'i

DOUGLAS S. CHIN
Lt. Governor, State of Hawai'i