SENATE JOINT RESOLUTION
No. 131

STATE OF NEW JERSEY
219th LEGISLATURE

INTRODUCED NOVEMBER 12, 2021

Sponsored by:
Senator SHIRLEY K. TURNER
District 15 (Hunterdon and Mercer)

SYNOPSIS

Designates October 23 of each year as "Aromatic L-amino Acid Decarboxylase Deficiency Awareness Day".

CURRENT VERSION OF TEXT

As introduced.

A JOINT RESOLUTION designating October 23 of each year as "Aromatic L-amino Acid Decarboxylase Deficiency Awareness Day".

WHEREAS, The State of New Jersey supports protecting the health of young children and vulnerable populations, as well as educating the public and medical communities about rare diseases; and

WHEREAS, A rare disease is generally considered to be a disease that affects fewer than 200,000 people in the United States at any given time; and

WHEREAS, Aromatic L-Amino Acid Decarboxylase ("AADC") Deficiency is a life-limiting, severely debilitating genetic neurologic rare disease that significantly impacts a patient's development, motor skills, growth, cognition, and language skills; and

WHEREAS, AADC Deficiency results from an inherited genetic condition where patients lack the AADC enzyme that is required to create dopamine; and

WHEREAS, Without dopamine, patients may never achieve motor-skills milestones like holding their heads up, sitting, or standing, nor will the patient develop the ability to communicate or perform the most basic life needs; and

WHEREAS, Although some patients who are born with AADC Deficiency may be asymptomatic at birth, AADC patients typically experience symptoms within the first year of life such as developmental delay and involuntary eye movements; and

WHEREAS, A patient suspected of having AADC Deficiency is diagnosed with the disease through genetic and other biochemical tests; and

WHEREAS, AADC Deficiency affects approximately 1 in 100,000 people in the United States; and

WHEREAS, Caregivers of patients with AADC Deficiency are often responsible for the overall care of the patient due to the debilitating nature of this disease and patients may need life-long care; and

WHEREAS, The State of New Jersey can raise awareness of AADC Deficiency in the public and medical communities within this State in order to assist individuals suffering from AADC and their caregivers; now, therefore,

BE IT RESOLVED *by the Senate and General Assembly of the State of New Jersey:*

1. October 23 of each year is designated as "Aromatic L-amino Acid Decarboxylase Deficiency Awareness Day" in New Jersey.

2. The Governor is respectfully requested to annually issue a proclamation and call upon public officials, private organizations, and all citizens of this State to observe "Aromatic L-amino Acid

Decarboxylase Deficiency Awareness Day" with appropriate awareness activities and programs.

3. This joint resolution shall take effect immediately.

STATEMENT

This resolution establishes October 23 of each year as "Aromatic L-Amino Acid Decarboxylase Deficiency Day" in New Jersey.

The State of New Jersey supports protecting the health of vulnerable populations and young children, as well as educating the public and medical communities about rare diseases. A rare disease is generally considered to be a disease that affects fewer than 200,000 people in the United States at any given time. Aromatic L-Amino Acid Decarboxylase ("AADC") Deficiency is a life-limiting, severely debilitating genetic neurologic rare disease that significantly impacts a patient's development, motor skills, growth, cognition, and language skills. While some patients who are born with AADC Deficiency may be asymptomatic at birth, AADC patients typically experience symptoms within the first year of life such as developmental delay and involuntary eye movements. Caregivers of patients with AADC Deficiency are often responsible for the overall care of the patient due to the debilitating nature of this disease and patients may need life-long care. The State of New Jersey can raise awareness of AADC Deficiency in the public and medical communities within this State in order to support individuals with AADC Deficiency and their caregivers by designating this awareness day.