

Date of Hearing: July 8, 2021

ASSEMBLY COMMITTEE ON RULES
Ken Cooley, Chair
SCR 36 (Melendez) – As Amended April 22, 2021

SENATE VOTE: 37-0

SUBJECT: Aromatic L-amino Acid Decarboxylase (AADC) Deficiency Awareness Day.

SUMMARY: Proclaims October 23, 2021, as Aromatic L-Amino Acid Decarboxylase (AADC) Deficiency Awareness Day in the State of California, and encourages Californians to become better informed about and aware of AADC deficiency. Specifically, **this resolution** makes the following legislative findings:

- 1) 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. There are more than 6,800 rare diseases. Altogether, rare diseases affect an estimated 25,000,000 to 30,000,000 Americans.
- 2) Aromatic L-amino acid decarboxylase (AADC) deficiency is a life-limiting, severely debilitating genetic neurologic condition that significantly impacts a patient's development, motor skills, growth, and cognitive and language skills.
- 3) AADC deficiency results from an inherited genetic disease where patients lack the AADC enzyme that is required to create dopamine. Without dopamine, patients will never achieve motor milestones like holding their heads up, sitting, standing, or develop the ability to communicate or perform the most basic of life's needs. Patients are diagnosed through genetic and other biochemical tests.
- 4) AADC deficiency affects approximately one in 100,000 people in the United States. Patients suffering from AADC deficiency often have low muscle tone that is unexplained and not improving. There are also other symptoms, such as developmental delays and involuntary eye movements.
- 5) Caregivers of patients with AADC deficiency face many challenges and are often responsible for the overall care of the patient.

FISCAL EFFECT: None

REGISTERED SUPPORT / OPPOSITION:

Support

California Chronic Care Coalition
PTC Therapeutics

Opposition

None on file

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