
THIRD READING

Bill No: SCR 36
Author: Melendez (R), et al.
Amended: 4/22/21
Vote: 21

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

SOURCE: Author

DIGEST: This resolution proclaims October 23, 2021, as Aromatic L-Amino Acid Decarboxylase (AADC) Deficiency Awareness Day in the State of California.

Senate Floor Amendments of 4/22/21 make a technical correction and add co-authors.

ANALYSIS: 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. Some rare diseases are often severely debilitating, impact not only the patients but their families and loved ones, and have no effective treatments.
- 2) 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) 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) AADC deficiency affects approximately one in 100,000 people in the United States. Caregivers of patients with AADC deficiency face many challenges and are often responsible for the overall care of the patient.

This resolution designates October 23, 2021, as AADC Deficiency Awareness Day and encourages Californians to become better informed about, and aware of, AADC deficiency.

Comments

According to the author,

SCR 36 seeks to raise awareness about Aromatic l-amino acid decarboxylase (AADC) deficiency—a debilitating ultra-rare disease that afflicts infants—by declaring October 23, 2021, AADC Deficiency Awareness Day.

By promoting AADC deficiency awareness, the Legislature can help to better inform parents, caregivers, health care providers and the public, with the goals of increased early diagnoses, faster, more effective treatment, and finding a cure.

FISCAL EFFECT: Appropriation: No Fiscal Com.: No Local: No

SUPPORT: (Verified 4/19/21)

California Chronic Care Coalition

OPPOSITION: (Verified 4/19/21)

None received

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