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**ACR-92 Aromatic L-amino Acid Decarboxylase (AADC) Deficiency Awareness Day.** (2021-2022)

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**Assembly Concurrent Resolution No. 92**

**CHAPTER 123**

Relative to aromatic l-amino acid decarboxylase deficiency awareness.

[ Filed with Secretary of State August 19, 2022. ]

**LEGISLATIVE COUNSEL'S DIGEST**

ACR 92, Petrie-Norris. Aromatic L-amino Acid Decarboxylase (AADC) Deficiency Awareness Day.

This measure would proclaim October 23, 2022, as Aromatic L-Amino Acid Decarboxylase (AADC) Deficiency Awareness Day in the State of California.

Fiscal Committee: no

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, There are more than 6,800 rare diseases. Altogether, rare diseases affect an estimated 25,000,000 to 30,000,000 people; and

WHEREAS, Some rare diseases are often severely debilitating, impact not only the patients but their families and loved ones, and have no effective treatments; and

WHEREAS, 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; and

WHEREAS, 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; and

WHEREAS, 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; and

WHEREAS, AADC deficiency affects approximately one in 100,000 people in the United States; and

WHEREAS, Caregivers of patients with AADC deficiency face many challenges and are often responsible for the overall care of the patient; and

WHEREAS, An AADC deficiency clinical trial is scheduled at Lucile Packard Children's Hospital Stanford, concluding by July 15, 2023; and

WHEREAS, The Legislature can raise awareness of AADC deficiency in the public and medical communities; now, therefore, be it

Resolved by the Assembly of the State of California, the Senate thereof concurring, That the Legislature designates October 23, 2022, as AADC Deficiency Awareness Day and encourages Californians to become better informed about, and aware of, AADC deficiency; and be it further

Resolved, That the Chief Clerk of the Assembly transmit copies of this resolution to the author for appropriate distribution.