



ACR-190 Amyotrophic Lateral Sclerosis Awareness Month. (2023-2024)

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Assembly Concurrent Resolution No. 190

CHAPTER 102

Relative to Amyotrophic Lateral Sclerosis Awareness Month.

[Filed with Secretary of State June 14, 2024.]

LEGISLATIVE COUNSEL'S DIGEST

ACR 190, Dixon. Amyotrophic Lateral Sclerosis Awareness Month.

This measure would proclaim the month of May 2024 as Amyotrophic Lateral Sclerosis Awareness Month in California.

Fiscal Committee: no

WHEREAS, Amyotrophic Lateral Sclerosis ("ALS") is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord; and

WHEREAS, The life expectancy for an individual with ALS is between 2 and 5 years after the date on which the individual receives an ALS diagnosis; and

WHEREAS, ALS occurs throughout the world, with no racial, ethnic, gender, or socioeconomic boundaries; and

WHEREAS, Approximately 2,400 Californians are afflicted with ALS at any time; and

WHEREAS, The cause of ALS is unknown in up to 90 percent of cases; and

WHEREAS, Approximately 10 percent of cases have a strong known genetic driver; and

WHEREAS, On average, the period between the date an individual first experiences symptoms of ALS and the date the individual is diagnosed with ALS is more than 1 year; and

WHEREAS, The onset of ALS often involves muscle weakness or stiffness and the progression of ALS results in the further weakening, wasting, and paralysis of the muscles of the limbs and trunk and the muscles that control vital functions, such as speech, swallowing, and breathing; and

WHEREAS, ALS can strike individuals of any age, but predominantly strikes adults; and

WHEREAS, It is estimated that tens of thousands of individuals in the United States have ALS at any given time; and

WHEREAS, Based on studies of the population, slightly more than 5,600 individuals are diagnosed with ALS each year, and approximately 15 individuals are diagnosed with ALS each day, in the United States; and

WHEREAS, Between 2015 and 2040, the number of ALS cases around the world is expected to increase by nearly 70 percent; and

WHEREAS, The majority of individuals with ALS die of respiratory failure; and

WHEREAS, In the United States, military veterans are significantly more likely to be diagnosed with ALS than the general public; and

WHEREAS, As of the date of introduction of this resolution, there is no cure for ALS; and

WHEREAS, The spouses, children, and family members of individuals living with ALS support these individuals with love, day-to-day care, and more; and

WHEREAS, An individual with ALS or their caregivers can be required to bear significant costs for medical care, equipment, and home care services as the disease progresses; now, therefore, be it resolved

Resolved by the Assembly of the State of California, the Senate thereof concurring, That the Legislature of the State of California hereby proclaims May of 2024 as Amyotrophic Lateral Sclerosis Awareness Month in California; and be it further

Resolved, That the Legislature affirms its dedication to (1) ensuring that individuals with ALS have access to effective treatments as soon as possible, (2) identifying the risk factors and causes of ALS to prevent new cases, (3) empowering individuals with ALS to engage with the world in the way they want, (4) reducing the physical, emotional, and financial burdens of living with ALS, and (5) ensuring all individuals with ALS and their caregivers receive high quality services and supports that benefit them; and be it further

Resolved, That the Legislature commends the dedication of the family, caregivers, friends, organizations, volunteers, researchers, providers and caregiving professionals across the nation that are working to improve the quality and length of life for those living with ALS and the development of treatments and cures that reach patients as soon as possible; and be it further

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