



Senator Scott Jiu Wo Kawasaki

Alaska State Senate

Sponsor Statement SB 256

May as ALS Awareness Month

“An act establishing May as Amyotrophic Lateral Sclerosis Awareness month; and providing for an effective date.”

The month of May is recognized as National ALS Awareness Month. ALS is also known as Amyotrophic Lateral Sclerosis or Lou Gehrig's disease. ALS was first identified in 1869. In the 155 years since, there is still no effective treatment and no cure.

ALS is a neurodegenerative disease that affects the nerve cells in the brain and spinal cord that control voluntary muscle movement and breathing. ALS is a 100% fatal disease. There is no cure for ALS.

ALS is a rare disease, affecting approximately 5 in 100,000 people. Approximately 30,000 people in the United States are currently living with ALS and approximately 60 people in Alaska are currently living with ALS. 90 % of patients diagnosed with ALS have no family history of disease. Only 10% of patients have familial/hereditary ALS.

ALS may strike at any age, but most people who have ALS are between 40 - 70. There are currently only 3 medications that slow the progression of ALS, and one medication that targets familial ALS specifically. These medications only extend life expectancy by a few months.

ALS causes the motor neurons in the central nervous system to degenerate over time and die. This affects a person's ability to talk, walk, and breathe. People with ALS will eventually lose their ability to speak, become paralyzed, and lose the ability to breath on their own. ALS patients die from respiratory failure.ponsor

The mean survival for someone diagnosed with ALS is two to five years. Every 90 minutes someone is diagnosed with ALS, and every 90 minutes someone dies from it. Veterans are 1 ½ to 2 time more likely than non-service members to be diagnosed with ALS. There is no single test to diagnose ALS, it is diagnosed only after numerous other conditions have been ruled out (a delayed diagnosis results in delayed treatment/start on medications). It can take a patient over a year to get an ALS diagnosis.

ALS symptoms vary. In limb onset ALS, it may manifest as weakness in a patient's hand or foot, arm or leg. In bulbar onset ALS, it may manifest as trouble speaking or swallowing. There currently is no known cause of ALS. 100% of ALS patients are unaware of the cause of their disease. Why is ALS Awareness month in Alaska important?

ALS Awareness is important on numerous levels. Raising awareness of this disease and the need for funding for research to help discover a treatment that stops progression of ALS (and hopefully one day a treatment that will reverse the damage caused by ALS). Raising awareness so more doctors are aware of ALS and its symptoms, leading to an earlier diagnosis. Raising awareness to increase funding for ALS care. Alaska does not have a single neurologist who specializes in ALS and does not have an ALS care clinic. ALS

patients in Alaska (who are not paralyzed yet by it and are still able to travel) have to travel out of state every three months to visit their ALS Care Clinic, which is a team (consisting of a neurologist, respiratory therapist, speech pathologist, physical/occupational therapist, nutritionist) who special in ALS care and work with patient on a care plan to help manage ALS symptoms. Lastly, raising awareness about what ALS is and shining a light on the people who are battling this disease is important to help bring understanding to the challenge.