F I S C A L I M P A C T R E P O R T

SPONSOR Maestas **ORIGINAL DATE** 2/22/19 **LAST UPDATED** **HB** 642

SHORT TITLE Amyotrophic Lateral Sclerosis Support **SB**

ANALYST Chenier

APPROPRIATION (dollars in thousands)

Appropriation		Recurring or Nonrecurring	Fund Affected
FY19	**FY20**		
	$100.0	Recurring	General Fund

(Parenthesis ( ) Indicate Expenditure Decreases)

SOURCES OF INFORMATION
LFC Files

Responses Received From
No responses Received

SUMMARY

Synopsis of Bill

House Bill 642 appropriates $100 thousand from the general fund to the Department of Health for expenditure in FY20 to contract with a state chapter of a national organization that supports individuals living with amyotrophic lateral sclerosis (also known as Lou Gehrig's disease) and those individuals' caregivers by providing access to assistive technology, supporting multidisciplinary care and providing support for families affected by amyotrophic lateral sclerosis.

FISCAL IMPLICATIONS

The appropriation of $100 thousand contained in this bill is a recurring expense to the general fund. Any unexpended or unencumbered balance remaining at the end of FY20 shall revert to the general fund.

SIGNIFICANT ISSUES

An article from the National Institutes of Health stated the following:

> Amyotrophic lateral sclerosis (ALS) is a group of rare neurological diseases that mainly

involve the nerve cells (neurons) responsible for controlling voluntary muscle movement. Voluntary muscles produce movements like chewing, walking, and talking. The disease is progressive, meaning the symptoms get worse over time. Currently, there is no cure for ALS and no effective treatment to halt, or reverse, the progression of the disease.

ALS belongs to a wider group of disorders known as motor neuron diseases, which are caused by gradual deterioration (degeneration) and death of motor neurons. Motor neurons are nerve cells that extend from the brain to the spinal cord and to muscles throughout the body. These motor neurons initiate and provide vital communication links between the brain and the voluntary muscles.

Messages from motor neurons in the brain (called upper motor neurons) are transmitted to motor neurons in the spinal cord and to motor nuclei of brain (called lower motor neurons) and from the spinal cord and motor nuclei of brain to a particular muscle or muscles.

In ALS, both the upper motor neurons and the lower motor neurons degenerate or die, and stop sending messages to the muscles. Unable to function, the muscles gradually weaken, start to twitch (called fasciculations), and waste away (atrophy). Eventually, the brain loses its ability to initiate and control voluntary movements.

Early symptoms of ALS usually include muscle weakness or stiffness. Gradually all muscles under voluntary control are affected, and individuals lose their strength and the ability to speak, eat, move, and even breathe.

Most people with ALS die from respiratory failure, usually within 3 to 5 years from when the symptoms first appear. However, about 10 percent of people with ALS survive for 10 or more years.

OTHER SUBSTANTIVE ISSUES

In 2016 the Centers for Disease Control and Prevention estimated that between 14,000 - 15,000 Americans have ALS. ALS is a common neuromuscular disease worldwide. It affects people of all races and ethnic backgrounds.
There are several potential risk factors for ALS including:

- **Age**. Although the disease can strike at any age, symptoms most commonly develop between the ages of 55 and 75.
- **Gender**. Men are slightly more likely than women to develop ALS. However, as we age the difference between men and women disappears.
- **Race and ethnicity.** Most likely to develop the disease are Caucasians and non-Hispanics.

Some studies suggest that military veterans are about 1.5 to 2 times more likely to develop ALS. Although the reason for this is unclear, possible risk factors for veterans include exposure to lead, pesticides, and other environmental toxins. ALS is recognized as a service-connected disease by the U.S. Department of Veterans Affairs.

Sporadic ALS: The majority of ALS cases (90 percent or more) are considered sporadic. This means the disease seems to occur at random with no clearly associated risk factors and no family history of the disease. Although family members of people with sporadic ALS are at an increased risk for the disease, the overall risk is very low and most will not develop ALS.

EC/al