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FISCAL IMPACT REPORT

SPONSOR Maestas **LAST UPDATED** 3/11/23
ORIGINAL DATE 2/11/23
SHORT TITLE Amyotrophic Lateral Sclerosis Support **BILL NUMBER** Senate Bill 261
ANALYST Klundt

APPROPRIATION* (dollars in thousands)

Appropriation		Recurring or Nonrecurring	Fund Affected
FY23	FY24		
	\$500.0	Recurring	General Fund
	\$150.0	Nonrecurring	Senate Bill 192, General Fund

Parentheses () indicate expenditure decreases.
 *Amounts reflect most recent version of this legislation.

ESTIMATED ADDITIONAL OPERATING BUDGET IMPACT* (dollars in thousands)

	FY23	FY24	FY25	3 Year Total Cost	Recurring or Nonrecurring	Fund Affected
		\$13.9	\$13.9	\$27.8	Recurring	General Fund

Parentheses () indicate expenditure decreases.
 *Amounts reflect most recent version of this legislation.

Relates to House Bill 290

Sources of Information

LFC Files

Response Received
 Department of Health

SUMMARY

Synopsis of Senate Bill 261

Senate Bill 261 (SB261) appropriates \$500 thousand from the general fund in fiscal year 2024 (FY24) to contract with a state chapter of a national organization that supports individuals living with amyotrophic lateral sclerosis and those individuals' caregivers by providing access to assistive technology, supporting multidisciplinary care, and providing support for families affected by amyotrophic lateral sclerosis. Any unexpended or unencumbered balance remaining at the end of fiscal year 2024 shall revert to the general fund.

FISCAL IMPLICATIONS

Senate Finance Committee substitute for Senate Bill 192, the supplemental appropriations bill, contains \$150 thousand to contract to serve families and individuals living with amyotrophic lateral sclerosis

The appropriation of \$500 thousand contained in this bill is a recurring expense to the general fund. Any unexpended or unencumbered balance remaining at the end of FY24 shall revert to the general fund. Although SB261 does not specify future appropriations, establishing a new grant program could create an expectation the program will continue in future fiscal years; therefore, this cost is assumed to be recurring.

DOH reported an annual administrative cost of \$13.9 thousand to oversee the appropriation for this bill. LFC assumes the administrative cost would be deducted from the \$500 thousand contained in SB261.

SIGNIFICANT ISSUES

According to the Mayo Clinic, Amyotrophic lateral sclerosis (ALS) is a progressive nervous system disease that affects nerve cells in the brain and spinal cord, causing loss of muscle control.

ALS affects the nerve cells that control voluntary muscle movements such as walking and talking (motor neurons). ALS causes the motor neurons to gradually deteriorate, and then die. Motor neurons extend from the brain to the spinal cord to muscles throughout the body. When motor neurons are damaged, they stop sending messages to the muscles, so the muscles cannot function.

ALS is inherited in 5 percent to 10 percent of people. For the rest, the cause is not known. Researchers continue to study possible causes of ALS. Most theories center on a complex interaction between genetic and environmental factors.

According to the CDC as of 2017, an estimate of over 31,000 patients are living with ALS in the United States. On average 5,000 new patients are diagnosed every year with this disease. Because records on ALS have not been kept throughout the country, it is hard to estimate the number of ALS cases in the United States. ALS is more common in men than women. ALS is age related; most people find out they have it when they are between 55 and 75 years of age, and live from two to five years after symptoms develop. How long a person lives with ALS seems to be related to age; people who are younger when the illness starts live slightly longer. DOH reported it is hard to estimate the number of ALS cases in the state of New Mexico because there is not a statewide surveillance system. However, the current prevalence is believed to be between five and seven cases within a population of 100 thousand.

DOH also reported the average annual cost per patient is estimated to be \$143 thousand. Patients with ALS incur an average of \$92 thousand in direct costs and \$51 thousand in indirect costs.

The New Mexico Chapter of the ALS Association offers assistance to guide people with ALS and family members to additional resources.

Additionally, the University of New Mexico Health Sciences Centers (UNMHSC) also offers clinics on the 2nd and 4th Wednesday of every month according to the New Mexico Chapter of the ALS Association. UNMH Multidisciplinary ALS Clinic serves patients in New Mexico who have been diagnosed with ALS. The clinical team includes neurology, physical therapy, occupational therapy, speech therapy, nutrition, respiratory therapy, and social work.

In June 2019, The ALS Association, along with The New Mexico Chapter, welcomed the University of New Mexico Hospital to the nonprofit organization's Certified Treatment Center of Excellence Program, establishing the UNMH Multidisciplinary ALS Clinic as meeting the highest levels of established national standards of care in the management of Amyotrophic Lateral Sclerosis (ALS).

Finally, DOH stated, "SB261 is relatively narrow in describing the organization that will need to be contracted for the expenditure of appropriated funds. However, the contract will be subject to the NM Procurement Code, and the Department of Health will therefore be required to go through the RFP process to contract with an organization that supports individuals living with ALS."

KK/al/ne/hg