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## Chapter 42, 2022 Regular Session (S.F. No. 3372-Third Engrossment) – Appropriating money for amyotrophic lateral sclerosis research and caregiver support program

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**Section 1 256.9755** establishes the caregiver support programs.

**Subd 1** states that the goal of the area agencies on aging and the caregiver support programs is to support family caregivers of persons with amyotrophic lateral sclerosis (ALS) who are living in the community, by promoting caregiver support programs that serve people in their homes, providing, within available funding, support services to enable family caregivers to access support programs, and providing information, education, and training for coping with caring for a person with ALS.

**Subd 2** the Minnesota Board on Aging is required to allocate to area agencies on aging the state funds in a manner consistent with federal requirements. The board shall give priority to those areas where there is a high need of respite services.

**Subd 3** funds allocated to an area agency on aging for caregiver support services must be used in a manner consistent with the National Family Caregiver Support Program to reach family caregivers of persons with ALS, except that the funds can be used for persons both under and over the age of 60. The funds must be used to provide social, nonmedical, community-based services, and activities that provide respite for caregivers.

**Subd 4** requires a progress report by January 15, 2025, and every other January 15 thereafter, by the Minnesota Board on Aging to the chairs and ranking minority members of the human services committees. The progress report must include metrics of the use of the grant program.

**Section 2** appropriates funds for ALS research.

**Paragraph (a)** appropriates \$20,000,000 in fiscal year 2023 to the Office of Higher Education to award competitive grants to applicants for research into ALS. The

commissioner may work with the Minnesota Department of Health to administer the grant program. Not more than \$400,000 may be used by the commissioner to administer the program.

**Paragraph (b)** requires grants to be awarded to support clinical and translational research related to ALS. Research topics may include, but are not limited to, environmental factors, disease models, clinical studies, assistive technologies, and cognitive studies.

**Paragraph (c)** specifies that eligible applicants include research facilities, universities, and health systems located in Minnesota. When reviewing proposals, the commissioner shall make an effort to avoid approving a grant for an applicant whose research is duplicative of an existing grantee's research.

**Paragraph (d)** requires the commissioner to submit a report beginning January 15, 2023, and annually thereafter until January 15, 2027, specifying the applicants receiving a grant, the amount and purpose of the grants, and the amount unexpended. The report must also include relevant findings, results, and outcomes of the grant program.

**Paragraph (e)** provides that this is a onetime appropriation and does not cancel until June 30, 2026.

**Section 3** appropriates \$5,000,000 for the caregiver support program under section 1. Programs receiving funding under this section must include an ALS-specific respite service in the caregiver support program. This is a onetime appropriation and is available until June 30, 2026.