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State of Minnesota

HOUSE OF REPRESENTATIVES

NINETY-SECOND SESSION

H. F. No. 3604

02/21/2022 Authored by Lislegard, Hortman, Sandstede, Ecklund, Sundin and others
The bill was read for the first time and referred to the Committee on Health Finance and Policy

1.1 A bill for an act
1.2 relating to health; establishing ALS caregiver support and respite services grants;
1.3 establishing ALS services grants; establishing ALS research grants; requiring
1.4 reports; appropriating money; proposing coding for new law in Minnesota Statutes,
1.5 chapters 145; 256.

1.6 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

1.7 Section 1. [145.9275] AMYOTROPHIC LATERAL SCLEROSIS RESEARCH
1.8 GRANTS.

1.9 Subdivision 1. Grant program established. (a) The commissioner of health shall
1.10 establish a grant program to award grants by June 30 of each year to institutions in Minnesota
1.11 for research into amyotrophic lateral sclerosis (ALS). Grants shall be awarded to support
1.12 clinical and translational research related to ALS. Research topics may include but are not
1.13 limited to environmental factors, disease mechanisms, disease models, biomarkers, drug
1.14 development, clinical studies, precision medicine, medical devices, assistive technology,
1.15 and cognitive studies.

1.16 (b) Eligible applicants for the grants are research facilities, universities, and health
1.17 systems located in Minnesota. Applicants must submit proposals to the commissioner by
1.18 March 31 of each year.

1.19 (c) An ALS account is established in the special revenue fund. Appropriations to the
1.20 commissioner for the program are for transfer to the account. Money in the account is
1.21 appropriated to the commissioner to make grants and to administer the grant program under
1.22 this section. Appropriations from the account do not cancel and are available until expended.

2.1 Subd. 2. **Report.** Each January 15, the commissioner shall submit a report to the chairs
2.2 and ranking minority members of the legislative committees having jurisdiction over health,
2.3 specifying the institutions receiving grants under this section and the purposes for which
2.4 the grant funds were used.

2.5 **EFFECTIVE DATE.** Subdivision 1 is effective July 1, 2022. Subdivision 2 is effective
2.6 July 1, 2023.

2.7 Sec. 2. **[256.4795] AMYOTROPHIC LATERAL SCLEROSIS SERVICES GRANTS.**

2.8 Subdivision 1. **Grant program established.** The commissioner of human services shall
2.9 establish the amyotrophic lateral sclerosis (ALS) services grant program to support, improve,
2.10 or expand the treatment of ALS.

2.11 Subd. 2. **Administration.** The commissioner of human services, as authorized by section
2.12 256.01, subdivision 2, paragraph (a), clause (6), shall contract with the Minnesota, North
2.13 Dakota, South Dakota chapter of the ALS Association to (1) serve as a fiscal host for the
2.14 money appropriated for the purposes described in this section, and (2) develop guidelines,
2.15 criteria, and procedures for awarding grants.

2.16 Subd. 3. **Eligible applicants.** To be eligible for a grant under this section, the applicant
2.17 must be an ALS treatment facility located in Minnesota and recognized by the ALS
2.18 Association as a certified treatment center of excellence, as a recognized treatment center,
2.19 or as an affiliated clinic.

2.20 Subd. 4. **Applications.** Entities seeking grants under this section shall apply to the fiscal
2.21 host under contract with the commissioner. The grant applicant must include a description
2.22 of the project that the applicant is proposing, the amount of money that the applicant is
2.23 seeking, and a proposed budget describing how the applicant will spend the grant money.

2.24 Subd. 5. **Reports.** (a) Grant recipients shall provide the fiscal host with a report about
2.25 the activities funded by the grant program in a format and at a time specified by the fiscal
2.26 host. The fiscal host shall require grant recipients to include in the grant recipient's report
2.27 at least the information necessary for the fiscal host to meet the fiscal host's obligation under
2.28 paragraph (b).

2.29 (b) The fiscal host shall provide the commissioner with a report that describes all of the
2.30 activities and outcomes of projects funded by the grant program in a format and at a time
2.31 determined by the commissioner.

3.1 **Sec. 3. [256.9755] CAREGIVER SUPPORT PROGRAMS.**

3.2 Subdivision 1. **Program goals.** It is a goal of all area agencies on aging and caregiver
 3.3 support programs to support family caregivers of persons with amyotrophic lateral sclerosis
 3.4 (ALS) who are living in the community by:

3.5 (1) promoting caregiver support programs that serve Minnesotans in their homes and
 3.6 communities;

3.7 (2) providing, within the limits of available funds, the caregiver support services that
 3.8 enable the family caregiver to access caregiver support programs in the most cost-effective
 3.9 and efficient manner; and

3.10 (3) providing information, education, and training to respite caregivers and volunteers
 3.11 about caring for, managing, and coping with care for a person with ALS.

3.12 Subd. 2. **Authority.** The Minnesota Board on Aging shall allocate to area agencies on
 3.13 aging the state funds which are received under this section for the caregiver support program
 3.14 in a manner consistent with federal requirements. The board shall give priority to those
 3.15 areas where there is a high need of respite services as evidenced by the data provided by
 3.16 the board.

3.17 Subd. 3. **Caregiver support services.** Funds allocated under this section to an area
 3.18 agency on aging for caregiver support services must be used in a manner consistent with
 3.19 the National Family Caregiver Support Program to reach family caregivers of persons with
 3.20 ALS, except that such funds may be used to provide services benefiting people under the
 3.21 age of 60 and their caregivers. The funds must be used to provide social, nonmedical,
 3.22 community-based services and activities that provide respite for caregivers and social
 3.23 interaction for participants.

3.24 Subd. 4. **Report.** By January 15, 2025, and every other January 15 thereafter, the
 3.25 Minnesota Board on Aging shall submit a progress report about the caregiver support grants
 3.26 in this section to the chairs and ranking minority members of the legislative committees
 3.27 and divisions with jurisdiction over human services. The progress report must include
 3.28 metrics of the use of the grant program.

3.29 **Sec. 4. APPROPRIATION; CAREGIVER SUPPORT PROGRAMS.**

3.30 (a) \$5,000,000 in fiscal year 2023 is appropriated from the general fund to the
 3.31 commissioner of human services for the Minnesota Board on Aging for the purposes of
 3.32 caregiver support programs under Minnesota Statutes, section 256.9755. Programs receiving

4.1 funding under this section must include an ALS-specific respite service in their caregiver
4.2 support program.

4.3 **Sec. 5. APPROPRIATION; ALS RESEARCH GRANTS.**

4.4 \$10,000,000 in fiscal year 2023 is appropriated from the general fund to the commissioner
4.5 of health for amyotrophic lateral sclerosis (ALS) research grants under Minnesota Statutes,
4.6 section 145.9275.

4.7 **Sec. 6. APPROPRIATION; ALS SERVICES GRANTS.**

4.8 \$10,000,000 in fiscal year 2023 is appropriated from the general fund to the commissioner
4.9 of human services for amyotrophic lateral sclerosis (ALS) services grants under Minnesota
4.10 Statutes, section 256.4795.