



April 17, 2024

To: Senate Human Services Committee

Re: SF 5335 – Human Services Budget Omnibus

Dear Chair Hoffman and Vice Chair Fateh and Committee Members,

On behalf of the ALS Association, I am writing in support of Sen. Hoffman's inclusion of \$5 million dollars in ALS Caregiver funds in SF 5335 and to thank Sen. Hoffman for his continued commitment to the ALS community in Minnesota.

Amyotrophic lateral sclerosis (ALS) is an always fatal progressive neurodegenerative disease that slowly robs a person's ability to walk, talk, eat, and eventually breathe. At any given time, more than 600 Minnesotans are living with ALS with 2 people diagnosed and 2 people dying each week. Despite significant progress in understanding ALS over the past few decades, breakthrough treatments remain elusive and people living with ALS urgently need more effective treatments than what is available today.

Since it began in November 2023, the Tomassoni Caregiver Grants program, named for former state senator David Tomassoni, has supported 75 families with 15 more families currently in the intake process. These caregiver grants provide an average annual average of \$20,000 per family to cover costs associated with in-home care, as well as education for personal and professional caregivers.

Being a family caregiver, while a fulfilling role, can consume a great deal of physical, mental and emotional energy. Ensuring these unpaid caregivers receive respite provides them with an opportunity to care for themselves – something that's often overlooked because we know that while caring for a person with ALS, caregivers often neglect their own needs. Caregiver burnout makes the task of caregiving very difficult, if not impossible. It can lead to resentment on the part of the caregiver, and even illness. The Tomassoni Caregiver grants gives full-time family caregivers the opportunity to tend to their own well-being with the trust and reassurance that a qualified and knowledgeable caregiver is taking care of their loved one.

Caregivers are essential in ALS care, and without them many living with ALS would not be able to live in their own homes, and the legislature's investment and continued support of the Tomassoni Caregiver Grants is greatly appreciated.

Thank you for your time and service.

Sincerely,

Sarah Sanchez
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The ALS Association
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