



April 16, 2024

To: Senate Higher Education Committee

Re: SF 5326 - Higher education licensure and grant provisions funding and related policy changes establishment

Dear Chair Fateh and Vice Chair Putnam and Committee Members,

On behalf of the ALS Association, I am writing in support of SF 5326, specifically the language addressing the David J. Tomassoni ALS Research Grant Program, and encourage it be included in the final higher education omnibus finance bill.

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.

Continued investment in research stimulates drug discovery and helps to increase clinical trial access and efficacy. It assists in developing new treatment approaches that optimize the use of telehealth and assistive technologies. And as we gain a greater understanding of the underlying factors that lead to the development of ALS, research will allow us to leverage genetic testing and counseling to prevent ALS.

The David J. Tomassoni ALS Research Grant Program, named after the late Minnesota Senator, provides funding for research contributing to the prevention, functional improvement, and curative efforts for people with Amyotrophic Lateral Sclerosis (ALS). To date, the Tomassoni ALS Research Grant has awarded \$4 million to 5 grantees. Research areas include brain and cervical cord imaging as a biomarker, identification of protective factors for spinal motor neurons and biorepository to support ALS research in Minnesota.

SF 5326 updates the Tomassoni Grant to expand the eligibility of applicants and the areas of research that may qualify for the grant and extends the date by which funds must be used by three years. These changes will ensure that the researchers and institutions doing this vital research will meet the requirements in the grant application.

People living with ALS and their families deserve hope. By continuing the commitment to ALS research, we can improve the quality of life and help people live longer, prevent or delay the harms of ALS, and ultimately find a cure.

Thank you for your time and consideration of this critical legislation.

Sincerely,

Sarah Sanchez  
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The ALS Association  
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