



April 9, 2024

To: House Higher Education Finance and Policy Committee

Re: HF 5299 - Funding and related policy changes provided to certain higher education licensure and grant provisions, fees established, and money appropriated

Dear Chair Pelowski and Vice Chair Wolgamott and Committee Members,

On behalf of the ALS Association, I am writing in support of HF 5299, specifically the language addressing the David J. Tomassoni ALS Research Grant Program.

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.

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  
Managing Director, Advocacy  
The ALS Association  
[sarah.sanchez@als.org](mailto:sarah.sanchez@als.org)