

May 16, 2024

To: Chair Fateh, Chair Pelowski and Conferees of the Higher Education Finance and Policy Bill

Re: HF 4024/SF 4003 – Higher Education Finance and Policy Bill

Dear Chair Fateh, Chair Pelowski and members of the conference committee,

On behalf of the ALS Association, I am writing to thank the conference committee for the inclusion of \$15 million dollars reappropriated for the David J. Tomassoni ALS Research Grant Program and of the clarifying language to the grant program included in the bill. However, we encourage to committee conferees to consider an increase to the proposed 5% administrative costs allowed to administer the grant program. Administering a grant program of this complexity would require an organization to create the infrastructure to provide outreach to researchers, grant funds and maintain contact with selected grantees to ensure efficacy of the program.

The ALS Association understands how essential it is for these grant dollars to go to ALS research, but we also know how imperative it is that these funds go to thoroughly vetted and reviewed organizations, institutions, and individuals. As stewards of taxpayer dollars, we take this role very seriously – and allowing us to use 7% on grants of this importance would ensure that we are doing our due diligence as the administrators of these funds. We ask the conference committee to amend current language in the A-24-0346 Conference Committee Agreement so that at line 2.6-2.7 reads "other similar organizations may use up to a total of seven percent of this appropriation for administering costs."

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. The language included in HF 4024 will ensure that organizations, institutions, and individuals doing this important research will meet the qualifications of the grant program.

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 support of ALS research in Minnesota.

Sincerely,

Sarah Sanchez Managing Director, Advocacy The ALS Association sarah.sanchez@als.org