



March 27, 2024

To: Honorable Members of the Senate Committee on Health and Human Services

Re: Support for SF 3927 - Rare Disease Advisory Council Membership Modifications and Appropriation

Dear Chair Wiklund, Ranking Member Utke and Members of the Committee,

On behalf of the ALS Association, I am writing in support of SF 3927, which would increase funding to the Rare Disease Advisory Council (RDAC) and allow for the membership of issue experts as needed when researching and advising on an issue area.

Any conditions that affect fewer than 200,000 Americans are considered rare. Rare diseases are present across a broad spectrum of medical conditions, including amyotrophic lateral sclerosis (ALS). ALS is a fatal progressive neurodegenerative disease that slowly robs a person's ability to walk, talk, eat, and eventually breathe. There is currently no cure or significantly effective treatment options for ALS. But, like other rare diseases, ALS patients face many unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition to battling for fair insurance coverage for their treatment and care.

Minnesota demonstrated its commitment to the rare disease community by establishing the Rare Disease Advisory Council in 2022. The Council has successfully represented the needs of the rare disease community by raising awareness and giving patients and their loved ones a unified voice in Minnesota state government. RDAC has offered valuable input to state leaders on rare disease research, access to treatment and best practices for the care of those living with rare diseases.

Minnesota's RDAC represents enormous value to the ALS Association and the community we serve by allowing legislators to hear directly from a diverse group of stakeholders interested in identifying and solving pressing challenges. SF 3927 would align the RDAC budget as a new state agency with that of other comparable agencies. The increased base funding will also allow the Council to create physician support tools to address delayed diagnosis, increase the capacity for community outreach and support of patient advocacy groups and develop best practice guidance for rare disease care management.

Once again, on behalf of The ALS Association and people living with ALS and their families in the state of Minnesota, we thank you for considering SF 3927. Please support this legislation for Minnesota residents living with rare diseases.

Sincerely,

Sarah Sanchez
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The ALS Association
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