

Tuesday, March 14th, 2023

The Honorable Zack Stephenson
The Honorable Charlie Kotyza-Witthuhn
House Committee on Commerce Finance and Policy

Re: Support for H.F. 1978, to require health plans to cover of biomarker testing

Thank you, Chairman Stephenson, Vice-Chair Kotyza-Witthuhn, and members of the committee. On behalf of all ALS patients, including the hundreds of patients we serve in Minnesota, we respectfully request your support for H.F. 1978. As with many diseases, early detection and treatment are crucial to changing the trajectory of the disease and preventing severe illness, and that is no different with amyotrophic lateral sclerosis. Passage of H.F. 1978 will ensure that more people across Minnesota can get the life-saving early warning signs through biomarker testing and reduce the long-term burden and the uncertainty of an ALS diagnosis.

Amyotrophic lateral sclerosis (ALS) is a fatal progressive neurodegenerative disease that slowly robs a person's ability to walk, talk, eat, and eventually breathe. The cost of care for someone living with ALS is astronomical, with annual out-of-pocket expenses reaching upwards of \$250,000 per year. The cost associated with biomarker testing should not be added to this financial burden.

Additionally, delays in diagnosis are a significant problem for our community. Many ALS patients go a year or more after symptom onset before being correctly diagnosed. Although there are no known cures or significantly effective treatment options for ALS, early diagnosis is essential in managing the disease, as treatments are liable to be more effective in early disease stages, and earlier detection allows patients and clinicians to anticipate likely complications before they occur.

As new and potentially more effective ALS therapies are being developed and novel biomarkers are being identified, the importance of early diagnosis and biomarker testing coverage will grow significantly. We strongly support the inclusion of biomarker testing in all health insurance plans and Medicaid coverage.

Thank you for your time and your consideration of this critical legislation. For all these reasons, we respectfully request your support for H.F. 1978.

Sincerely,
Sarah Sanchez
Managing Director, Advocacy
The ALS Association



OUR VISION: Create a world without ALS.

OUR MISSION: To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

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