

April 3, 2024



Chair Morse and Members of the Committee:

Thank you for your time and for your consideration of our budget request to help Michiganders living with ALS and their families. Amyotrophic Lateral Sclerosis (ALS), sometimes called “Lou Gehrig’s Disease,” is an always-fatal, progressive, neurodegenerative disease with no known cure. It typically takes 1 – 2 years to diagnose, at which point a patient has an average life expectancy of 2 – 5 years.

The ALS Association is America’s largest nonprofit focused on helping people living with ALS, and we have one overriding goal: making ALS livable until we can cure it. What does making ALS livable mean?

It means that the roughly 1,000 Michiganders who currently have ALS can remain in their homes under family-based care instead of needing to spend down their savings to bankruptcy in order to enroll in the state’s Medicaid program and access its more generous benefits.

It means that Michiganders living with ALS have access to the medical equipment they need to improve and maintain their quality of life, from power-wheelchairs that allow for mobility to speech devices that let them to talk with loved ones even after ALS has taken their ability to physically speak.

Perhaps most importantly, it means that Michiganders living with ALS can spend their last months focused on their family and friends instead of spending that time focused on navigating the red tape of insurance denials and terrified of medical debts that will outlive them.

On behalf of those 1,000 Michiganders and their families who are living with ALS every day, we are urging the state to appropriate up to \$1,000,000 to complement The ALS Association’s long-standing but insufficiently funded care service programs.

In Michigan, The ALS Association provides always-free ALS care services to people living with ALS and their families up to the limit of our donation-dependent budget. Our care service programs include: in-home visits and caregiver training; ALS patient and family member support groups; the no-cost loan or gift of Durable Medical Equipment (DME) ranging from common disposable items to expensive reusable items such as wheelchair ramps and eye-gaze speech devices; grants for home renovations needed to progress-in-place with the disease; support for hospital-based multidisciplinary ALS clinics; transportation stipends for clinical visits; and grants for home care/respite care.

Currently, due to the limits of our donation-dependent budget, we are able to directly assist approx. 620 of the 1000 Michiganders diagnosed with ALS. State funding would allow us to reach more Michigan families living with ALS, and to provide higher levels of support to those we already serve. With cases of ALS projected to increase by 69 percent over the next 25 years

as anticipated advancements in diagnostics and treatments turn a fatal disease into a chronic one, more patient families than ever will need these services to bend but not break under the logistical, emotional, and financial weight of this disease. In states like Indiana, Ohio, Maryland, Pennsylvania, Tennessee and Virginia, recently passed state funding for ALS care services is helping patients living with ALS remain in their own homes under family-based care instead of spending down to insolvency, qualifying for Medicaid, and seeking in-patient care.

With our longstanding presence in the Michigan ALS community and an on-the-ground understanding of the evolving needs of Michigan families struggling with ALS, The ALS Association is seeking a direct line-item or departmental grant of up to \$1,000,000 in the upcoming FY24-25 budget to expand our existing ALS care service capacity, reach more Michiganders living with ALS, and increase the level of support we're able to provide those families we already serve. The ALS Association stands ready to work with state officials and staff to ensure total transparency for every dollar spent, with specific objectives, deliverables, and evaluation metrics.

Securing funding for ALS patients in Michigan is not only critical to their well-being, but it is also a cost-effective measure that would save Michigan significant funds on an annual basis by delaying or eliminating entirely the need for patients to enroll in Medicaid.

Because each family is different, financial situations vary. However, with no cure and a duration that averages 2-5 years from diagnosis to death, the out-of-pocket costs for a person living with ALS almost always eclipse a family's ability to pay, and typically lead to the depletion of retirement savings, college accounts, home equity, go-fund-me efforts, and eventually medical bankruptcy. Additionally, the person living with ALS, and usually their spouse, often have to leave their jobs and sacrifice their salary and employer sponsored health insurance.

While the cause of ALS is still unknown, studies prove that military veterans are nearly twice as likely to develop and die from ALS than members of the public. As a result, the Veteran's Administration (VA) and Dept. of Defense have classified ALS as a service-related disease and have extended important benefits to active-duty personnel and veterans diagnosed with ALS. This is a critical issue for Michigan, as it has a large population of military personnel and veterans, totaling over 568,000. The ALS Association provides care coordination and support to meet all immediate needs of Michigan veterans as they wait for VA benefits to kick in.

If you would like any additional information, or have any questions, please do not hesitate to reach out. Thank you for considering this request.

Sincerely,

Alex Meixner
Managing Director of Advocacy
The ALS Association
alex.meixner@als.org