May 14, 2025

The Honorable Stephen Huffman, Chair
Senate Health Committee
Finance Hearing Room
Columbus, OH

Dear Chairman Huffman, Vice Chair Johnson, Ranking Member Liston, and Members of the Committee:

In support of individuals living with Amyotrophic Lateral Sclerosis (ALS, commonly known as Lou Gehrig's disease) in Ohio, we urge you to support the Governor's request and HB 96 (page 4667) as passed by the House to include ALS Care Services Funding in the state operating budget. This funding request of $1,000,000 each fiscal year is critical to the well-being of ALS patients and will be cost-effective for the state, reducing the need for Medicare, Medicaid, and other state assistance programs.

Since 2023, Ohio has provided funding to the ALS Association through the Ohio Department of Health. With this support, the ALS Association has delivered compassionate, direct care to nearly 450 families affected by ALS in Ohio. Continued funding will allow us to sustain essential programs and services that support hundreds of families across the state.

At any given time, nearly 1,000 people in Ohio are living with ALS, a fatal, progressive neurodegenerative disease with no known cure or effective treatment. Additionally, for unknown reasons, military veterans are nearly twice as likely to be diagnosed with ALS. The U.S. Department of Defense recognizes ALS as a service-related disease, and veterans make up approximately 10–15% of the individuals we serve.

ALS progressively robs individuals of their ability to walk, talk, eat, and eventually breathe. The cost of medical care for a person with ALS can exceed $82,500 per year. Many families exhaust their retirement and life savings to cover these expenses, ultimately turning to the state for assistance.

Currently, with the support of community partners, individual donors, charitable foundations, and some local governments, the ALS Association provides high-quality, comprehensive, and streamlined programs—free of charge—to individuals with ALS and their families. These services include:

- Augmentative and Alternative Communication (AAC)
- Durable Medical Equipment
- Ramp and Virtual Home Modification Safety Assessments
- Care Coordination, including staff resources and referrals
- ALS Multidisciplinary Clinics, with direct clinic support and staffing
- Education programs for families and clinicians
- Support groups
- Caregiver support

With ALS cases projected to increase by 69% over the next 25 years, and anticipated advancements in treatment turning a fatal disease into a chronic one, more families than ever will require these vital services. State funding will help reach underserved areas, including rural communities, and address the most significant needs of families—respite care and home health services.

These programs would also allow caregivers to remain in the workforce longer, enabling them to maintain income, pay taxes, and retain workplace-sponsored insurance benefits.

We deeply appreciate your ongoing support and thank you for considering this critical funding request.

If you have any questions or concerns, please contact Lindsay Jack at Lindsay.jack@als.org.

Sincerely,

Lindsay Jack

Lindsay Jack
Managing Director, Advocacy
The ALS Association
Lindsay.Jack@als.org