



Ohio House Finance Committee  
March 27, 2023  
The ALS Association  
Interested Party Testimony

Chair Edwards, Vice Chair LaRe, Ranking Member Sweeney and members of the House Finance Committee: thank you for allowing me the opportunity to testify today. My name is Lisa Bruening and I am the Director of Care Services at the ALS Association serving Northern Ohio.

In support of people living with Amyotrophic Lateral Sclerosis (ALS, commonly known as Lou Gehrig's disease) in the State of Ohio, we are urging you to support The ALS Association's request to pass the ALS Care Services Funding amendment, which would appropriate \$2,000,000 in the FY 2024 – 2025 State Budget. Obtaining this funding is critical to the well-being of ALS patients and will be cost-effective for the state, saving significant funds with the reduction in the need for Medicare, Medicaid, and other state assistance programs.

At any given time, more than 1,100 people are living with ALS in Ohio. ALS is a fatal, progressive, neurodegenerative disease with no known cure or effective treatment options. Additionally, our military veterans, for unknown reasons are nearly twice as likely to be diagnosed. The U.S. Department of Defense recognizes ALS as a service-related disease. Military veterans make up approximately 10-15% of the people we serve.

ALS robs a person of their ability to walk, talk, eat, and finally breathe. Throughout the course of their illness, people with ALS need significant medical care, which can easily exceed \$82,500 a year<sup>1</sup>. Many families deplete their retirement and life savings to meet these needs and ultimately turn to the State for assistance.

Currently, with the support of various community partners, individual donors, charitable foundations, and some local governments, The ALS Association maintains high-quality, comprehensive, and streamlined programs, providing services to people with ALS and their families, free of charge. Examples include:

- One-on-one support and home visits by a social worker.
- Multidisciplinary clinics & telemedicine programs.
- Assistive Technology Loaner Program.
- Durable Medical Equipment Loaner Program.
- Transportation assistance
- Support groups; and more.

With cases of ALS projected to increase by 69 percent over the next 25 years<sup>2</sup> and anticipated advancements in treatments, turning a fatal disease into a chronic one, more families than ever will need this vital support. Furthermore, the state funding would allow for the ability to reach all underserved areas, like rural communities throughout the state, as well as meet the most significant need of families—

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<sup>1</sup> \$63,848 in 2012, when the Lewin study was published, is \$82,536.54 in 2023 as the dollar had an average inflation rate of 2.36% per year between 2012 and today, producing a cumulative price increase of 29.27%.

<sup>1</sup> Cost of Amyotrophic Lateral Sclerosis, Muscular Dystrophy, and Spinal Muscular Atrophy in the United States. The Lewin Group, Inc, March 2012.

<sup>2</sup> Traynor, Chio, Geiger, Price, Calvo, Arthur "Projected increase in amyotrophic lateral sclerosis from 2015 to 2040." Nature Communications, Volume 7, id. 12408 (2016)

respite care and home health services. These programs would allow for caregivers to remain in the workforce longer; continuing to collect much-needed income, pay taxes, and collect workplace-sponsored insurance benefits. These are issues we hope to address with the passage of the ALS Care Services Funding amendment.

Thank you again for the opportunity to testify and it is our sincere hope that you will support The ALS Association in the fight against ALS. I would be happy to take any questions.