Testimony on ALS Care Services Amendment in the 2024 & 2025 Operating Budget for People Living with ALS (Amyotrophic Lateral Sclerosis)

House Finance Committee
The Honorable Jay Edwards, Chair
The Honorable Jeff LaRe, Vice Chair

Columbus, Ohio
Ohio Statehouse

Presented by:

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Good morning Chairman Edwards, Vice Chair LaRe, Ranking Minority Member Sweeney and members of the Finance Committee. My name is Marlin Seymour and I am the Executive Director of The ALS Association Central & Southern Ohio Chapter.

I am part of the only non-profit organization in Ohio that provides direct and local case management from nurses and social workers, medical & speech equipment, technology and assistive devices, patient grants, and support groups to people living with ALS across the state of Ohio. All of the services we provide are offered **FREE of CHARGE** through donations. We are here today representing people with ALS in Ohio and their families in support of the ALS Care Services $2,000,000 funding request in the 2024-2025 Operating Budget.

Mr. Chairman, thank you for allowing us to submit testimony and to testify on behalf of this request. Amyotrophic Lateral Sclerosis or ALS, robs people of their ability to do the everyday things that you and I take for granted. Most people who develop ALS are between the ages of 40 and 70 but the average age of diagnosis is 55. We regularly serve people who are in their 30's and 40's however - - people who are single and people with young families. ALS does not discriminate in who it strikes, and can impact anyone at any time, regardless of their age, gender, race or ethnicity. Only 5-10% of cases are considered genetic or "familial" – where 1 or more people in a family have been diagnosed with ALS.

Thanksgiving of 1994 **my** family became a **"member"** of the ALS community when my mother was diagnosed – it was devastating news. Nine months later, I was ecstatic to learn that there was an organization that would help provide support, education and understanding. I started attending the local support group in Columbus and then - only three months later - **my mom's journey with ALS ended - she died just 12 months after being diagnosed**. ALS is ravaging – it takes away someone's physical abilities…including the ability to breathe….typically over a very short period of time.

Our organization provides services and care in the ALS community and all of that is done, **FREE OF CHARGE.** ***Simply put, through our free programs, we are able to offer a better quality of life, while those with ALS are living through this terrible illness***. We provide a wide range of services that may not otherwise be available to patients, their families, or their caregivers. Those services include case management by nurses and social workers, support & education groups, equipment loan programs, bereavement groups, children's programs, newsletters, home visits, and patient grants, among other services. In addition, we provide paid, credentialed healthcare professionals who help staff multidisciplinary ALS clinics at the Cleveland Clinic, the Louis Stokes VA Medical Center – both in Cleveland -- and the OhioHealth ALS Clinic, in Columbus and the University of Cincinnati ALS Clinic in Cincinnati. All of these programs are **tangible** and **provide improved quality of life** at a time when they are desperately needed, **as unfortunately our patient numbers across Ohio have grown by 40% in the last five years.**

With numbers growing so significantly in such a short period of time, we have not been able to keep up with the demand for services. By supporting this amendment in the Operating Budget to provide $2,000,000, you will be making a tangible difference in the lives of people like the some of the ones noted in the "Statement of Support" document we've submitted. **Those statements of support are very personal and authentic and cut straight to the point of why it is so critical to have an organization like ours in the community, providing direct outreach and help, across the state.**

This small investment for people with ALS in Ohio will yield significant cost savings to the state, by helping keep them in their homes longer and out of expensive long-term care facilities. As the numbers of people we are serving continues to rise each year, state support will help keep pace with growing needs and improve the lives of ALS families throughout Ohio.

Thank you Mr. Chairman and distinguished subcommittee members for your time and attention.