

Good morning, Chairman Edwards, Vice Chair LaRe, Ranking Member Sweeney and members of the Finance Committee. I am Judy Jasper, I live in Galloway, and I am a former caregiver for my husband, Dan Jasper, who passed away just one year ago from ALS. Thank you for the opportunity to share my testimony in support of the ALS Care Services Amendment to the State Operating Budget for fiscal years 2024 and 2025.

As the primary caregiver for my husband, I know well the invaluable services that the ALS Association's Ohio Chapters provide to individuals diagnosed with this always-fatal disease. My husband was "lucky" as he lived 5 years after his diagnosis. Most others, including many outstanding people with ALS we met through the Association, were not as fortunate.

In Dan's 5 years of living with ALS, he went from being a very independent, active, and involved husband, father and hardworking man to one who became completely paralyzed and eventually unable to breathe on his own. The progression was fast. For the last 2 years of his life, he required round-the-clock care. As his condition worsened, he had to stop working at a company he enjoyed for over 30 years. I left a career I loved to be his caretaker 24/7, yet realize it was the best decision I ever made. Thankfully, our 3 children were able to arrange flexible work schedules with their employers that would allow them to rotate their days off to assist me with caring for their dad at home.

Despite his physical deterioration, Dan was completely mentally alert and active, contributing to his family life, community, and his workplace. A man of faith, despite living in the prison of a paralyzed body, he never complained to anyone of his condition, and he would do anything he could to support the good work of the ALS Chapter – including rallying around fundraising efforts during the Covid shut down to keep the good work of the Chapter going, at a time when he was physically at his worst. We experienced the invaluable support of the Chapters personally, and I wish to tell you about it.

Though we lived in Columbus, Dan was diagnosed at the Cleveland Clinic. His neurologist, knowing that Columbus had an ALS Association accredited clinic at OhioHealth, suggested that we reach out to the Central & Southern Ohio Chapter to be connected with this clinic since it was nearby. I immediately called the ALS Chapter, and my phone call was returned in less than 5 minutes. It was the fastest reply we had ever received in the entire lengthy journey to diagnosis. We were immediately assigned a Care Services Coordinator who connected us with a network of nurses, a social worker, speech therapist, physical and occupational therapists, nutritionist, and neurologist that formed Dan's multidisciplinary ALS clinical team that would accompany him throughout his entire journey. Dan's Care Services Coordinator helped us with finding the support we needed each step of the way, particularly in assisting with equipment, services and grants for items NOT covered by insurance.

Even with insurance, ALS is a breathtakingly costly disease. There are many items ALS patients need that are simply not covered by insurance. The ALS Association was able to lessen our financial burden with their equipment loan program, which provided key items that Dan needed daily – items like a wheelchair, respiratory equipment and assistive speech technology. These are big-ticket items that have long lead times – and, with this rapidly progressing disease, people with ALS do not have time on their side. Additionally, equipment like speech-generating devices that use eye-gaze technology to allow people with ALS to communicate, require updates, become obsolete and are expensive to replace. All this equipment, and so much more, are loaned by the Chapters to people with ALS. This equipment isn't something you can easily transport in the back of your car; and for many who live in rural areas, they are underserved, as delivery must be arranged. This equipment also needs a place to be inspected,

cleaned, and staged. Funding support to the Chapters would ensure a more comprehensive lending inventory and resources to get it in the hands of those who need it when they need it.

The ALS Chapters also provide quality of life grants. These grants range from \$1,200 – 2,000 annually per person living with ALS, based on availability of funds. These are patient reimbursement grants that assist with equipment and supplies and care that are not covered by insurance. The grants can also be used to provide co-pay assistance for medications and tube-feeding nutrition. In Dan's case, we were able to use this grant to help with eye gaze equipment, specialized eating utensils, and nutritional formula when he could no longer swallow. \$1,200 a year doesn't seem like a lot when medical expenses can cost up to \$250,000 a year out-of-pocket during advanced stages of the disease, but it certainly does help with small items throughout the year that enhance the quality of life of someone living with ALS.

Since the beginning of our ALS journey, the growth in the patient numbers at the Chapters has almost doubled. I've seen this each year at our annual Walks to Defeat ALS. There is an incredible showing of support from those impacted by ALS, however, many of the individuals who participate in the fundraising are the same ones who are shouldering the financial burdens I've just outlined. State funding would help to anchor the fundraising efforts of the communities in which people with ALS live.

Dan was fortunate to be able to live at home with us until the day he passed. The support of the ALS Chapters – his Care Coordinator and clinical team and resources, the equipment loan program and grant program along with the sacrifices of our family and friends made this possible. It was the best possible scenario for our family and for Dan. It's also the best possible scenario for the State. As Lisa has highlighted, investments made to keep people with ALS in their homes results in significant cost savings to the state as well as improving the lives of ALS families throughout the state. This requested budget funding is a win-win for ALS and the state.

Thank you for your thoughtful consideration.