

Good morning, Chairman Edwards, Vice Chair LaRe, Ranking Member Sweeney and members of the Finance Committee. I am Heather Merkle and I live in Dublin. I'm glad I can come before you today to share my testimony in support of the ALS Care Services Amendment to the State Operating Budget for fiscal years 2024 and 2025.

In March of 2021, I was diagnosed with ALS at the age of 48, after noticing weakness in my dominant right hand. Prior to this weakness, I had led a healthy and active life as a wife, mother, and former elementary school teacher. I always tried to eat healthily, participated in exercise classes, and had healthy yearly check ups.

As my family and I coped with this devastating news, I learned about the path of progression and the inevitable future loss of use of my arms and legs, and possibly my voice. My husband and I realized our family's two story home would not be a good fit for my future health, so we moved our family into a nearby ranch-style house within a few months of being given my diagnosis.

During those first few months, I learned about the local ALS Association. I sent an email to ask how to register with the group and for advice on home modifications for our new house. That same day I received a cheerful welcoming message from a Care Services Coordinator, Charisse Bailey, who stated, "I would love to assist you!". She kindly thanked me for my contact information and set up a time to chat. Charisse later sent me a welcome email describing her background and offering to help me "with anything". She also included her contact information and links to helpful websites covering the chapter, services, exchange groups, the CDC, informational sites, and "spoon therapy". "Spoon Therapy" is a concept for managing and conserving one's limited energy - kind of like "choosing your battles". She also mailed me a kit of adaptive kitchen utensils and a packet of written information that explained the ALS chapter's loaner closet and yearly grant program to help with ALS expenses.

We soon learned what modifications would be needed for the master bathroom and we worked with a contractor and a local architect for planning. The costs of the project were significant. I applied for the grant to cover \$1,000 of the architectural design costs. It was wonderful news when my request was approved, and it helped us to stretch our construction budget. The modifications to the existing master bathroom to add an accessible sink, toilet, and shower took many months. When the new year rolled in during the construction process, I submitted one of the contractor's bills to the 2022 ALS grant program, and was thrilled to receive \$1,200 to help us complete the bathroom project.

On a regular basis, our local ALS chapter is wonderful in sending out informational emails on news and monthly meetings. They also communicate when a useful item is available through donation. Last month I saw an email offering a free donated bedside lift. I quickly followed up and received the news that the lift was mine.

Due to my reduced stability when walking, I recently asked my Care Services Coordinator if the chapter had a rolling shower chair in the loan closet that I could use after our insurance denied my doctor's request for a \$4,000 shower chair. My coordinator informed me there wasn't one available, but if we purchased one we could apply for the 2023 grant to cover part of the cost. She also recommended a different, less expensive shower chair that was well liked by others with ALS and their care givers. As always, she encouraged me to contact her with any questions and to take care.

As losing the ability to speak is a common effect of ALS, my teenage son asked me to pursue voice banking, which he had read about when working on a school project. In 2021, I was able to have my voice banked with the help of a speech pathologist, meaning my own real voice can be used for my speech generating device. Last week my speech pathologist notified me that my insurance had denied her request for a rolling stand for the heavy device. However, she reached out to the ALS chapter and one is available in the loan closet that I will soon be using.

My family and I have learned that private insurance does not have the same interpretation of "medically necessary" as does anyone dealing with or providing care to a loved one with a disease like ALS. Being able to shower, use the restroom or even just get around your own home safely would seem to be basic necessities to most, but when adaptive aids or equipment are required, many of which can be extremely expensive, insurance companies are quick to declare a device to be "comfort care" versus "medically necessary", and therefore they won't cover the cost.

This is why the chapter's Care Coordinators, equipment loaner program and yearly grant program are each very important. My ALS Care Coordinator has emotionally supported me through my entire journey and I appreciate her willingness to help me with my needs. The grants and loaner program assist with offsetting the incredible financial burden of acquiring the equipment and aids that allow me to try to live a normal daily life.

Please provide your support for the \$2,000,000 ALS Care Services Amendment funding because it is a critical program in the lives of people facing this devastating disease.