Testimony on the 2026-2027 State Budget
Request for Support to Continue $1M Annually (in Executive Budget) for Support & Services to Those With ALS Across the State

House Health Committee
The Honorable Jean Schmidt, Chair
The Honorable Kellie Deeter, Vice Chair
The Honorable Anita Somani, Ranking Member

Ohio Statehouse
Columbus
March 5, 2025

Written Testimony Presented by:
Trish and Don Kennard
Person with ALS & Husband/Caregiver
Recipients of ALS United Ohio Services

Good morning, Chairwoman Schmidt, Vice Chair Deeter, Ranking Member Somani and members of the House Health Committee. My name is Trish Kennard, I am a mother, wife and daughter with ALS. My husband and I live in Dayton, Ohio. We have been asked to come before you today to share our story of my ALS journey in hopes of your keeping the $1M, annual allocation which is in the Executive Budget for services to people in Ohio with ALS.

I was diagnosed with ALS on April 25, 2024, at the age of 51. This diagnosis came after many months searching for the cause of the weakness in my left arm. I come from a family who unfortunately carries the Sod-1 gene which is one of many genes that cause ALS. It is a familial gene, and I am the 13th member of my family who has been diagnosed with ALS.

Later that day, we contacted our high school friend's mother who was the caregiver for her husband who also had ALS. She promptly connected us with ALS United Ohio. My husband phoned them the same day and spoke with their Social Worker, Melinda McGuire. Melinda showed up at our house the next day with all the medical equipment that we desperately needed at that time. She sat down with us and went over the services that they provided along with additional resources. We are very appreciative that our Ohio legislators provided support in the last budget to help us with equipment and so that we can have a healthcare professional who can lead us through this unfortunate situation.

ALS has robbed me of my independence, I can no longer feed or bathe myself as I have lost the use of all 4 limbs. Most recently, I lost the ability to fully expand my lungs, as a result I depend on the use of a breathing machine. I now require 24-hour care, because of this, we had to hire a private nurse to care for me while my husband is at work. Most of the physical effects of ALS are visible however the mental and emotional side effects of this terminal disease are just as devastating to my life. Knowing that I will most likely have passed before my kids get married or have kids, the hardship I feel that I put on my loved ones, not being able to hug my kids or my husband or even pet my dogs…ALS drastically impacts every part of my life.

With my limited mobility, I soon found myself in a wheelchair daily which prompted the need to purchase a wheelchair accessible van. We received a $1200 grant from ALS United Ohio to help with the purchase of the vehicle needed. Our local ALS United Ohio office keeps us well connected and informed of new and ongoing events and resources. Their equipment loan program has been a life saver as many of the needed items were not covered by insurance. Their loaner and grant programs have been vital the last 10 months as I am no longer able to work, our finances have been strained.

Donnie Kennard – Husband to Trish and Caregiver:

Trish and I have been together for 12 years and were recently married in November of 2024. Fourteen months ago, we were planning the last 1/3 of our lives together, last of our 6 kids were freshman in college, we finally lived alone, and we were looking for property to build our dream home on…Life has changed a lot since then, now providing the best care for Trish has been my number one priority. This is the most difficult experience and a blessing in its own way. Loving and caring for someone with ALS has taught me a lot about people and the important things in life but it has not come without consequences. For the past 10 months, I've averaged 4 hours of sleep a night, lost 25 pounds, rarely seen my 3 kids, and my thinning gray hair is definitely getting blamed on ALS.

The local services and 1 on 1 support we have received has done so much for so many Ohio families facing this devasting disease. Please provide your support in the Ohio State Budget by keeping the annual $1M, already allocated in the Executive Budget, for ALS families in Ohio.

Thank you.

Don and Trish Kennard