

**Ohio Medigap
House Bill 400, House Insurance Committee, 6/12/24
Erin Dittoe Oral Testimony**

Good morning, Chair Lampton, Vice Chair Barhorst and Members of the Insurance Committee:

Thank you for the chance to testify in support of House Bill 400. My name is Erin Dittoe, and I live in Lyndhurst, Ohio with ALS, my family and husband, Jim, who is with me today.

Thank you to Representatives Callender and Sweeney for introducing this important legislation.

Please close your eyes. Imagine you are unable to move or speak, try not to panic. Now add breathing difficulties. This is ALS.

When COVID came calling I was working long hours. Happy to have a job working from home. I noticed I felt like I was slurring my speech. Not wanting to be suspected of “day drinking,” I consulted my General Practitioner and scoured the internet. She referred me to a neurologist knowing symptoms linked me to Multiple Sclerosis, Parkinson’s, and ALS.

When my final diagnosis was delivered, I felt I knew more about ALS than the young neurologist that was there to “deliver world class care.” Offering no treatment options, he gave me 36 months to live. I was offered a handicapped parking pass and told “come back in six months.” He took my hope that morning.

With progress and rates different for each sufferer, I am lucky my ALS progression is slow. A popular person with ALS says, “you spend the first half of your illness wishing for slow progression and the second half wishing it would speed up.” For now, ALS leaves me with progressive weakness, poor balance, and garbled speech. Eventually walking, talking, and even breathing will become impossible.

ALS is an always fatal neurodegenerative disease. Imagine for a minute everyone in the room has ALS. Please look to your left, within 2 years that person would be dead. After diagnosis 50% of victims are dying within 2 years of diagnosis, 70% within five years, 90% within 10 years.

Hospitalized earlier this year after a severe asthma attack, I found myself unable to move, speak, or breathe. The emergency department, ICU, and stepdown unit were understaffed by over worked people. No department had a simple letter board to assist me with communication. I wished I possessed the equipment to manage my asthma more effectively at home. Proper early home treatment would have eliminated the \$30,000 five-day hospital visit.

During my hospital stay, I did not leave the bed. I needed too much care to even stand. Return to work became uncertain. Fortunately, I was atypical of most ALS patients. With weeks of intensive home physical and occupational therapy I regained most of my mobility. I was able to return to working at home.

I am under the age of 65 and now have enrolled in Medicare Parts A & B, as most do when they receive an ALS diagnosis. In Ohio, I cannot purchase a Medigap plan that would help cover the costs that Original Medicare does not. HB 400 would fix that and allow Ohioans under 65 living with ALS eligible to purchase Medigap coverage.

I find myself feeling relieved to finally have a diagnosis, many with rare illnesses do not. Fortunately, my function with ALS is high and my family can still work and care for me at home. But the crushing financial burdens of diagnostic testing, loss of work, the cost of new equipment are a part of my family’s lives now.

Because my husband still works, I am allowed to use his employer sponsored insurance. This helps cover many out-of-pocket costs. A lot of families are not in this position. With stress having an influence on ALS progression, patients must literally pick their battles.

Our family situation may change as my care needs increase. Without HB 400 in place, our time will be focused more on navigating the red tape of insurance denials and medical debt. HB 400 can help families with ALS across Ohio access medical equipment needed to improve and maintain their quality of life.

From power wheelchairs that allow for mobility, to speech devices. Equipment permits conversation and involvement with loved ones and medical providers after ALS has taken away their ability to physically move or speak.

Perhaps most importantly, HB 400 means that Ohioans living with ALS can spend their last months focused on what matters most, loving life with families and friends. Are you still imagining you are unable to move or speak? Did you panic when you couldn't breathe? Now imagine this never, ever, ends.

I think I know a little of what Lou Gehrig was feeling when he gave his "luckiest man" speech. I, too, have been extraordinarily fortunate; at this point, ALS has given me far more than it has taken from me.

Thank you for your time today, and I am grateful to be here.