Testimony on H.B. No. 24

Request for Support to Provide Medigap Policies for Medicare-Eligible Individuals Under the Age of 65

House Insurance Committee

The Honorable Brian Lampton, Chair

The Honorable Meredith Craig, Vice Chair

The Honorable Desiree Tims, Ranking Member

Ohio Statehouse

Columbus

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Good morning, Chairman Lampton, Vice Chair Craig, Ranking Member Tims, and members of the Insurance Committee. I am presenting this testimony on behalf of people with ALS in Ohio.

We ask you to support House Bill 24, to provide Medigap policies for Medicare-eligible individuals under the age of 65.

What is ALS?

Many of us know ALS as Lou Gehrig's disease, but ALS is also known as Amyotrophic Lateral Sclerosis (ALS). Best described as a "creeping paralysis," it's an insidious disease that takes away everything.

ALS is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord, slowly destroying the connections between the brain and the muscles. gradually robs people of the ability to speak, eat, walk, and eventually – to breathe.

Most people with ALS experience total paralysis and death within five years of diagnosis.

Ninety percent of ALS cases strike at random without regard to age, gender, ethnicity, income, profession, or prior health status. In other words, ALS can strike anyone, at any time. ALS United Ohio serves numerous people with ALS who are under age 65, even those in their 20s and 30s, including families with small children.

There is no cure for ALS.

Why Is This Bill Important for People with ALS?

ALS is not only fatal – it's financially devastating. It is estimated that the out-of-pocket expenses for people in late-stage ALS can reach more than $120,000 each year – that's $10,000 a month! This extreme financial burden comes at a time when simply living each day with the disease is overwhelming for patients and their family caregivers.

More than 20 years ago, the federal government eliminated the two-year waiting period before people under age 65 with ALS could receive Medicare benefits due to disability. Yet today, people under age 65 with ALS still often cannot get a Medigap policy that would help them supplement their Medicare coverage.

Medicare Supplement plans, also known as Medigap, help cover out-of-pocket costs not covered by Original Medicare (Parts A and B), such as copayments, coinsurance, and deductibles. These plans may also cover some services not covered by Original Medicare such as deductibles for inpatient hospital stays and outpatient services, Part B excess charges, coverage for emergency medical care received outside the U.S., skilled nursing facility care, and more.

People living with ALS already face numerous challenges and obstacles to obtaining healthcare, including:

- Waiting periods for durable medical equipment through Medicare or private insurance
- Insurer limits on type or quantity of device provided
- High deductibles and co-insurance for the equipment and medications
- Lack of coverage for specialized equipment with necessary tailoring to specific needs
- General lack of insurance access or being under-insured due to facility placement.

The following is a portion of a testimonial from one of our ALS caregivers that illustrates the immense burdens insurers often place on people living with this disease:

> "Because our insurance company chose to preserve profits, we were turned down for equipment that Medicare calls the standard of care for ALS patients, so ALS United Ohio stepped in with help. Your organization loaned us so much equipment - canes, rollators, food utensils and pen holders, slide boards, cushions, toilet risers, two ventilators (turned down by our insurance company, despite it being the standard of care), a voice amplifier, computer for voice (our insurance company wanted to wait out Mary dying before they would agree to pay for a purchase of one), suction machine, nebulizer, and your grant helped us purchase a motorized wheelchair. We couldn't have afforded all these things, together, much less individually…thank God for your organization."

In conclusion, we believe that House Bill 24 aligns with the federal government's longstanding position on the urgency of providing Medicare coverage for people under age 65 with ALS. Please pass House Bill 24 to ensure private Medigap policies do their part to bring fairness in coverage for all people living with this devastating disease.

Thank you, Chairman Lampton, Vice Chair Craig, Ranking Member Tims, and distinguished Committee Members for your time, attention, and consideration.

About ALS United Ohio

ALS United Ohio provides people living with ALS, and their families, with **FREE** services and support to manage their diagnosis, that may not otherwise be available. Those services include case management by nurses and social workers, loans and purchases of essential equipment and communications devices, support & education groups, bereavement groups, children's programs, newsletters, home visits, and patient financial grants, among other services. We do not bill for services, nor receive insurance reimbursements.