



January 26, 2023

Delegate Michael J. Webert, Chair  
House Commerce and Energy Subcommittee Members

**RE: SUPPORT for Virginia H.B. 1640**

Dear Chair Webert and Members of the House Commerce and Energy Subcommittee;

On behalf of Virginians living with ALS, we respectfully request your support for House Bill 1640, which requires insurers issuing Medicare supplemental policies, typically known as Medigap, in the state to offer these policies at an affordable rate to all patients who are eligible for Medicare by reason of disability, including patients with amyotrophic lateral sclerosis (ALS) regardless of age.

The ALS Association is the largest philanthropic funder of ALS research in the world. The Association funds global research collaborations, assists people with ALS and their families through its nationwide network of staff, certified clinical care centers, and advocates for better public policies for people with ALS. The ALS Association builds hope and enhances quality of life while urgently searching for new treatments and a cure.

As you may already know, most people with ALS become eligible for Medicare Part A and B regardless of age the month their Social Security disability benefits start. Most patients choose to enroll in Medicare as their primary health insurance coverage. Medicare Part A covers hospital care, skilled nursing facility care, nursing home care, hospice, and home health services. Part B covers outpatient care, durable medical equipment, ambulance services and mental health.

However, for many of these patients, private supplemental Medigap insurance is needed to afford their deductibles and co-pays, as Medicare Part B covers 80 percent of medical care with no cap on out-of-pocket (OOP) expenses. Medigap plans may cover some of the costs that fee-for-service Medicare does not cover such as copayments, coinsurance, and deductibles.

ALS patients have complex health care needs and face high out-of-pocket costs. The average annual OOP costs for ALS patients on Medicare can be as much as \$82,500<sup>12</sup>. This can present significant financial difficulties for ALS patients and their families, sometimes leading to heart-wrenching decisions such as whether to seek certain types of care or face bankruptcy.

Federal law does not require private insurance companies to sell Medigap plans to people under age 65. Most people who develop ALS are diagnosed between the ages of 40 and 70 with the average age being 55 at the time of diagnosis. The lack of federal protection for Medicare eligible patients under 65 has resulted in an uneven patchwork of state laws on this issue.

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<sup>1</sup> \$63,848 in 2012, when the Lewin study was published, is \$82,536.54 in 2023 as the dollar had an average inflation rate of 2.36% per year between 2012 and today, producing a cumulative price increase of 29.27%.

<sup>2</sup> Cost of Amyotrophic Lateral Sclerosis, Muscular Dystrophy, and Spinal Muscular Atrophy in the United States. The Lewin Group, Inc, March 2012.

Under the legislation (SB250) that Virginia enacted in 2020, Medigap insurers in the state have to offer at least one plan on a guaranteed-issue basis to Virginians who become eligible for Medicare prior to the age of 65 due to a disability. However, currently insurers are not required to offer Medigap to ALS patients under the age of 65 at the same rate as those that are 65 and over. People with ALS are paying nearly 250% more for their premiums than those 65 and over.<sup>3</sup> If passed, HB 1640 would fix this.

We believe that expanding Medigap coverage to Virginians with ALS under the age of 65 at an affordable price is an important and concrete way elected officials can support those with this life-altering, expensive, and devastating terminal disease.

Thank you for your time and for your consideration of this important legislation. For all these reasons we respectfully ask for your support for House Bill 1640.

Sincerely,

Lindsay Gill  
Managing Director, Advocacy  
The ALS Association  
[lindsay.gill@als.org](mailto:lindsay.gill@als.org)

Kara Nett Hinkley, MPP  
Vice President, State Policy  
The ALS Association  
[kara.hinkley@als.org](mailto:kara.hinkley@als.org)

Melanie Lendnal, Esq.  
Senior Vice President, Policy & Advocacy  
The ALS Association  
[melanie.lendnal@als.org](mailto:melanie.lendnal@als.org)

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<sup>3</sup> <https://www.medicare.gov/medigap-supplemental-insurance-plans>