Statement for the Record

Hearing to Consider the
Graham-Cassidy-Heller-Johnson Proposal

Senate Committee on Finance
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Submitted by:
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On behalf of people living with ALS and their caregivers, The ALS Association submits this statement for the record to oppose the amendment to the American Health Care Act (AHCA) proposed by Senators Lindsey Graham, Bill Cassidy, Dean Heller, and Ron Johnson.

The ALS Association, along with leading patient and provider groups, opposes the Graham-Cassidy proposal because it does not meet our core set of principles that health care must be accessible, affordable, and adequate.

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. The progressive degeneration of the motor neurons in ALS patients leads to disability and death of patients living with ALS – with an average life span of two to five years after diagnosis. The prevalence of ALS in the military is twice that of civilians.

The mission of The ALS Association is to discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest. Affordable, adequate care is vital to the patients we represent. Our Chapters work closely with Certified Centers of Excellence that offer multidisciplinary ALS clinics as well as provide a range of free services for people living with ALS and their families including: support groups, care services coordinators, equipment loan programs, assistive technology support and respite care grants. The ALS Association is a non-partisan organization that leads the fight to treat and cure ALS through global research and nationwide advocacy.

Unfortunately, the Graham-Cassidy proposal would negatively impact the access of people living with ALS and many Americans to adequate and affordable health coverage and care.

- **Patient Protections:** First, it would undermine nationwide protections for patients by offering states the ability to allow insurance companies to charge higher prices and place limitations on coverage (such as annual or lifetime caps) for those with preexisting conditions.

- **Premium Assistance:** Second, it would remove current premium assistance to help lower-income and moderate income families to afford to purchase the insurance that they need. This is especially important for people living with ALS who lose their job and insurance coverage after an ALS diagnosis but need to purchase health insurance for themselves and their families. Without premium assistance, many of these families could face serious financial stress or bankruptcy.

- **Medicaid:** Third, it would dramatically cut access to Medicaid health care by cutting and capping funds through block grants. Under Graham-Cassidy, states would be forced to change eligibility to fit their block grant funding or close enrollment in Medicaid when funds run out. This impacts not only people living with ALS who depend solely on Medicaid for coverage but also those patients who receive both Medicare and Medicaid.

- **Veterans:** Medicaid cuts would also harm veterans, as reported by 2017 research from the RAND Corporation, entitled “Veterans’ Health Insurance Coverage under the Affordable Care Act and Implications of Repeal for the Department of Veterans Affairs.” Although
many veterans do receive health care through the Department of Veterans Affairs (VA), a good number do not qualify or are unable to access VA care for a number of reasons. The RAND report notes that Medicaid expansion and marketplaces helped address gaps in health insurance coverage and contributed to lower rates of un-insurance among veterans. This is particularly important because the incidence of ALS in individuals is much higher for those who have served in military.

While we urge the Senate to reject Graham-Cassidy, we understand that improvements to the current system are needed. We greatly appreciate the bipartisan effort being spearheaded by Senators Alexander and Murray. In hearings in the Senate Committee on Health, Education, Labor, and Pensions, state regulators and governors of both parties offered solutions to help stabilize the insurance market. We urge the Finance Committee to join in these efforts to address issues within its jurisdiction to develop bipartisan solutions to these complex issues.

In closing, we encourage Congress to reject the Graham-Cassidy proposal because it will negatively impact people living with ALS who are part of the 133 million Americans with chronic diseases and disabilities and their family caregivers.

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