Statement for the Record

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The ALS Association
For the
House Veterans Affairs Subcommittee on Disability Assistance and Memorial Affairs
Legislative Hearing
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The ALS Association would like to thank Chairperson Luttrell, Ranking Member McGarvey, and the members of the House Veterans Affairs Subcommittee on Disability Assistance and Memorial Affairs for the opportunity to submit this statement for the record for the hearing on legislation in your subcommittee.

H.R. 1685 - *Justice for ALS Veterans Act* ensures that veterans and families who have made the ultimate sacrifice for this country receive benefits they cannot qualify for, through no fault of their own. Boosted Dependency and Indemnity payments grants peace of mind to current veterans living with ALS because they will know their families are supported after they are gone.

The ALS Association endorses this legislation and asks the Veterans Affairs Subcommittee on Disability Assistance and Memorial Affairs to consider and swiftly pass H.R. 1685 to deliver boosted DIC benefits surviving families have earned.

Background

Amyotrophic Lateral Sclerosis (ALS) is an always fatal neurodegenerative disease in which a person's brain loses connection with the muscles. People with ALS lose their ability to walk, talk, eat and eventually breathe. There is no cure, and the average life expectancy following diagnosis is 2-5 years.

Military veterans, regardless of branch of service, the era in which they served, and whether they served during a time of peace or a time of war, are at a greater risk of dying from ALS than those who have not served in uniform. For this reason, the Department of Veterans Affairs has labeled ALS as a presumptive service-connected disease rated at 100% disability upon diagnosis because ALS never improves and, in all cases, leads to total body paralysis.

While high-quality, multi-disciplinary care for ALS is provided by the Department of Veterans Affairs, military veterans living with ALS require care that extends outside of the clinical setting. Veterans living with ALS rely on their spouses, children, parents, and friends to provide the round-the-clock caregiving they need. The aggressiveness of ALS leaves many veterans totally incapacitated and reliant on family caregivers. It is an incredible price that veterans living with ALS and their loved ones pay as a result of their service to our country.

Support for H.R. 1685 the Justice for ALS Veterans Act

The ALS Association wholeheartedly supports H.R. 1685 - *Justice for ALS Veterans Act,* to ensure families of veterans are supported after their loved one passes.

The surviving spouses of veterans with a 100% disability rating are eligible to receive Dependency and Indemnity Compensation (DIC) payments from the VA after their loved one passes. However, to be eligible for the boosted DIC benefit, also known as the “kicker,” a veteran must live with a totally disabling condition for 8 years. With average life expectancy for ALS post-diagnosis ranging from 2-5 years, most veterans who have service-connected ALS will not meet the current criteria for the boosted DIC payment. This is a fixable injustice for veterans living with ALS who already have little time left with their loved ones.

The bipartisan Justice for ALS Veterans Act, sponsored by Representatives Brian Fitzpatrick (R-PA) and Chris Pappas (D-NH) ensures fairness by eliminating the 8-year survival requirement for veterans with ALS.

Families of veterans living with ALS who serve admirably as caregivers should not be penalized because of an ALS diagnosis that offers them less time with their loved ones than the current requirement stipulates. Ensuring this boosted benefit, which equates to little more than $300 a month for a surviving family, can make a marked difference.