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Veterans with ALS Reporting Act

The Challenge:

Amyotrophic Lateral Sclerosis (ALS) is a fatal neurodegenerative disease that can affect anyone, at any time, and progressively destroys a person's ability to control muscle movement. As the disease advances, people become trapped inside a body they can no longer control. Their minds, however, often remain sharp so that they are aware of their surroundings, the people in their lives, and what is happening to them.

The average life expectancy for a person living with ALS is just two to five years after diagnosis. There is no cure and few treatments that delay but do not stop disease progression.

Veterans are twice as likely to develop ALS. This is why the Department of Veterans Affairs (VA) recognizes ALS as a service connected disease and assigns a 100% disability rating upon diagnosis. However, far too little is known about *why* this link exists or what can be done to protect those who serve.

The Solution:

The Veterans with ALS Reporting Act will require the VA to study and provide critical data regarding ALS within the military and veteran communities. The bill would also require the VA to create a strategy to improve access to clinical trials for veterans with ALS and reduce incidence and prevalence of the disease. Specifically, this bill will:

- Provide data on the incidence and prevalence of ALS within veteran communities;
- Develop and test risk reduction strategies to lower the incidence and prevalence of ALS;
- Identify deficiencies in the resources and support that the CDC and VA provides to veterans with ALS;
- Create a strategy to develop pathways for those receiving ALS care within the VA to participate in clinical trials and research sponsored by the Department; and
- Track the prevalence of ALS in veterans using the ALS registry and biorepository of the Centers for Disease Control and Prevention.