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September 25, 2026

The Honorable Doug Collins
Secretary of Veterans Affairs
U.S. Department of Veterans Affairs

Dear Secretary Collins,

We respectfully write to request your consideration of amending Title 38 § 3.318 to include Inclusion Body Myositis (IBM) as a presumptive service-connected condition under VA regulation. Currently, Veterans diagnosed with Amyotrophic Lateral Sclerosis (ALS) after active duty receive presumptive service connection due to the disease's severity, progression, and association with military service. However, IBM - a progressive, incurable neuromuscular disease with significant molecular, clinical, and pathological similarities to ALS - remains excluded. As a result, Veterans diagnosed with IBM must navigate a lengthy and burdensome individualized claims process to establish direct service connection, despite growing evidence linking environmental exposures during military service to both ALS and IBM. Experts, including Dr. Thomas Lloyd of Baylor University (formerly of Johns Hopkins University) and Dr. Todd Cohen of the University of North Carolina, have highlighted the overlap between these conditions and the heightened exposure risks faced by military populations. According to a review by Dr. Julie Tomaska, a former member of the VA National Research Advisory Council, the prevalence of IBM among Veterans is approximately 189 per million, compared to 15 per million in the civilian population. The review also found that Veterans with IBM experience significantly higher mortality rates and often develop the disease 10 to 15 years earlier than the civilian population. Like ALS, IBM causes irreversible muscle weakness, loss of mobility and fine motor function, difficulty swallowing, and eventually respiratory failure. There is currently no cure or effective treatment. Yet unlike ALS patients, Veterans with IBM are not afforded a presumptive pathway to benefits, resulting in inconsistent adjudications and inequitable outcomes.

According to a July 2025 VA Freedom of Information Act response, 6,771 Veterans nationwide are currently receiving care for IBM through the VA healthcare system. The same response reflects a 221% increase in diagnosed cases since 2010, underscoring the growing impact of this debilitating disease and the need for further research into potential service-related and environmental causes. This issue also aligns with broader congressional efforts to better understand neurological diseases associated with toxic exposures, including work being done through the Healthy Brains Act and a current National Academies of Sciences, Engineering, and Medicine review examining links between military-related exposures and neurodegenerative conditions, including IBM. While we look forward to the findings of that review, we respectfully emphasize that Veterans currently suffering from IBM should not be left waiting for recognition and relief. Given the relatively limited but clearly identifiable affected population, we believe this matter may be appropriately addressed through the Department's existing regulatory authority.

Thank you for your continued commitment to our nation's Veterans and for your consideration of this important request.

Sincerely,

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