



Add Inclusion Body Myositis (IBM) to the VA's ALS Presumptive Rule

What is IBM?

IBM is a muscle disease characterized by chronic, progressive muscle inflammation accompanied by muscle weakness and difficulty swallowing. There is **no cure or FDA-approved treatment** for IBM.

Why are Veterans Being Denied Disability Benefits?

The prevalence of IBM among veterans is approximately **189 per million, compared to 15 per million** in the civilian population. To receive benefits, a veteran must prove a medical link between their disease and their military service. For a disease whose cause science has not yet identified, **that is not a high bar. It is an impossible one.**

- Veterans diagnosed with IBM must navigate a lengthy and burdensome individualized claims process to establish direct service connection.
- The appeals outlast the patients. A study of VA records — 732 veterans with IBM against 1,215 matched controls — found mean **survival of 8.5 years after diagnosis**, versus 15 years for controls. One veteran waited 10 years for his claim to be granted. Another waited 17.
- **VA does not formally track IBM, and there is no dedicated diagnostic code for it** — which produces repeated exams, incorrect ratings, and multiple appeals.

According to the VA, 306 IBM-related claims were submitted over five fiscal years: 251 were denied, only 55 were approved – an 82% denial rate

The Solution: Designate IBM as a “Presumptive” condition

- The purpose of VA presumptive status is to remove the burden of proof from veterans by automatically assuming that specific illnesses are service connected.
- **The VA has the regulatory authority to act today to begin tracking cases.** This doesn't preempt the National Academies review. It asks VA to be ready when the findings land, and to begin tracking cases now. Due to the rare incidence of IBM, this designation will have minimal budgetary impact.

Support Bipartisan Congressional Efforts to Make IBM Presumptive

HOUSE: Please cosign the [Dear Colleague letter](#) circulated by Representatives Gus Bilirakis (R-FL), Mike Thompson (D-CA), and Sarah Elfreth (D-MD).

SENATE: We expect a similar bipartisan letter in the Senate.



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IBM and ALS – Similar, but Different Policies

IBM shares ALS's profile as a rare, progressive, incurable neuromuscular disease elevated among veterans. However, unlike conditions like ALS, service connection for IBM is currently NOT presumptive. The mechanisms VA used to designate ALS as a presumptive condition serve as precedent for making IBM presumptive.

Today, more than **6,700 veterans are receiving VA care for IBM**, a 221% increase in diagnosed cases since 2010.

ALS - Presumptive

Veterans must have 90 days of qualifying service and an ALS diagnosis under 38 C.F.R. § 3.318

VS

IBM - NOT Presumptive

Veterans must prove a medical link between their disease and their service. **However**, IBM does not have a known cause.

Diagnosis Denied

U.S. Airforce veteran Jim Cressman was diagnosed with IBM in 2015. Since then, Jim has dedicated time to advocating for veterans with the disease and ensuring that people who do not know about the disease understand the challenges and limitations of living with myositis.

Watch the [documentary on YouTube](#) to learn more about Jim's story.



To learn more, visit www.myositis.org

Sources: Claims data (306/251/55) and VA statements: reporting in *The Clermont Sun*, July 8, 2026, and *Stars and Stripes*, May 29, 2026. Survival and cohort data: Liarski et al., *Military Medical Research*, 2025. Veterans in VA care and 221% increase: VA FOIA response, July 2025, cited in Rep. Bilirakis's June 24, 2026 letter to the Secretary of Veterans Affairs. Veteran prevalence estimate: Tomáška, *Inclusion Body Myositis Epidemiologic Review*, 2026. ALS presumption: 38 C.F.R. § 3.318.