

ALS is killing veterans

By Chris Mulholland

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Chris Mulholland led "The Mule Team" for the Walk to Defeat ALS in Virginia Beach on Oct. 3, 2021. The team raised \$11,000 for the ALS Association.

“Veterans are developing ALS in rates higher than the general population.

— VA Secretary Dr. James Peake, 2008

Do you know that ALS is a significant threat to the veterans' community?

Since 1910, multiple studies have shown that [the rate at which U.S. veterans develop amyotrophic lateral sclerosis](#) — also known as Lou Gehrig's disease — is twice as high as the American general population. Despite this, there's a shockingly low amount of awareness of the disease among the veteran community.

I should know. I was diagnosed with ALS in November 2020. Before then, my only acquaintance with ALS was the “ice bucket challenge”. After my diagnosis, I have made a point to ask every veteran I meet if they're aware of the link between military service and the likelihood of being stricken with ALS. I have yet to meet someone who says they do. That needs to change.

Every day in America, three veterans are diagnosed with ALS while another three die from it. The prognosis for a person diagnosed with ALS today is largely the same as it was 150 years ago — death in two to five years.

Towards the end, you are left almost incapable of communicating with the outside world except through your eyes.

I am a retired Marine and have been athletic all my life. I played soccer, rugby, and ice hockey. I refereed professional soccer and officiated all over the globe. I ran marathons and at the age of 60 was still bench pressing 300 pounds. Now I live in a wheelchair, barely able to lift a spoon to my mouth.

In 2007, Brig. Gen. Thomas “Mik” Mikolajcik, USAF (Ret.), [testified before Congress](#) about ALS: “If these soldiers were dying in the field — rather than quietly at home — we would leave no stone unturned. We would use the best existing resources to make sure they had whatever they needed to survive.” General “Mik” [died from ALS](#) on April 17, 2010.

In 2008, the Veterans Administration determined that military service is a presumptive causation of ALS for veterans. As veterans continue to reach the ages commonly associated with ALS, the rate of the disease will continue to increase in this population. I am evidence of that.

[According to a VA report](#), 1,055 veterans die from ALS each year. That means that since 9/11, three times more veterans have been lost to ALS than troops killed in combat in Iraq and Afghanistan combined (20,895 vs 6,896).

Interestingly, the Hampton Roads area of southeastern Virginia — where I and 234,476 of my fellow veterans live — is a “hotspot” for ALS cases.

More ominously, [a recent 2019 study](#) revealed that the prevalence of ALS among the Post-9/11 deployed veterans is 19.7 per 100,000 over 14 years compared to the US national average of 5.2 per 100,000. Even worse, for some Air Force personnel (pilots, aircraft crew, missile, and combat operation staff) the prevalence is substantially higher — 35.1 per 100,000!

And we still don't know why those in uniform bear an outsized burden from this disease.

The good news is that ALS gives veterans an automatic 100 percent disability rating from the VA. I have nothing but the highest of praise for the support I have received from the VA. From home modifications, to an accessible van, powered wheelchair, medical equipment and more, they have taken care of my every need. If you are diagnosed with ALS, do what I did and immediately contact your nearest VFW Service Officer. You — and your family — don't have any time to waste.

The bad news is that our regulatory process does not keep pace with the urgency of ALS. Drug trials drag on a decade or more when most ALS sufferers do not live nearly that long. A diagnosis of ALS is a virtual death sentence and comes with advice to patients to get their affairs in order and to tick off their bucket list while they still can.

ALS is designated as a rare disease not because so few people get it, but because ALS kills so quickly. As many as 30,000 Americans — approximately 5,000 of them veterans — have ALS, with 5,000 new cases diagnosed each year. However, if ALS patients lived for 10 years after diagnosis there would be 275,000 nationwide, a much more noticeable population.

60 percent of Americans don't know that ALS is always fatal. If you know of a veteran who has or had ALS, we need you in this fight. Too often ALS exists in the shadows, and those afflicted

pass so quickly they can't speak for themselves. Be their voice.

The veterans' community urgently needs answers and solutions for people with ALS.

I ask the VFW to use their influence and call upon Congress to fund early access to ALS investigational therapies, accelerate therapy development, and increase research on and development of interventions.

We can solve urgent health needs when we put our minds to it. The quick vaccine development during the pandemic proves that. I have already called both Senators Tim Kaine and Mark Warner. Please do the same.



Our nation must take all measures to ensure that our military men and women are at no greater risk of ALS than any other Americans.

Before I was diagnosed, I had no idea that ALS so disproportionately affects veterans. I have made it my personal mission to raise the awareness in the veteran community of the severity of ALS amongst us. Please help by telling other vets, friends, family — everyone — about the outsized threat of ALS to those who are or have served in uniform.

I will fight this battle to my dying breath.

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Editor's note: This is an Op-Ed and as such, the opinions expressed are those of the author. If you would like to respond, or have an editorial of your own you would like to submit, please contact Military Times managing editor Howard Altman, haltman@militarytimes.com.

Addendum: While the problem of veteran suicide is a significant problem in our nation, the suicide rate for veterans with ALS is even four times higher than that.

The Oped was also published in the following:

DefenseNews

Early Bird Brief; <https://www.defensenews.com/ebb>

Marine Corps Times

<https://www.marinecorpstimes.com/opinion/commentary/2021/10/28/als-is-killing-veterans/>

NavyTimes

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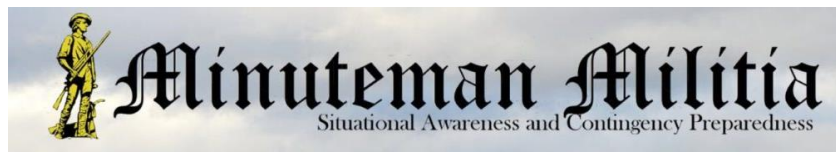
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DoD Times

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Oped made the Military Times, Virginia Pilot, Early Bird, Defense News, DOD Times, Marine Corps Times, Air Force Times, Navy Times, Army Times and Minuteman Militia!