

Veterans Committee, I AM ALS House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies FY 2021 Public Witness Testimony for the Record Monday, March 23, 2020

Dear Madam Chairwoman DeLauro, Ranking Member Cole, and Members of the Committee, we write this letter in support of the written testimony of Brian Wallach, an ALS patient and co-founder of I AM ALS.

As veterans with ALS and caregivers to veterans afflicted with ALS, we have a personal stake in increased DOD funding for robust ALS research. The number of veterans living with ALS has been noted at approximately 4,500. This number was identified as part of a study that supported the connection between ALS and military service. Today, we are seeing an increase in our active duty men and women, our brothers and sisters, diagnosed with ALS.

Our military careers, and especially our lives, are irrevocably changed with this diagnosis. As of this writing, there is no cure and no viable treatment to extend the quality and length of life. We as veterans and active-duty military members are being diagnosed in our 20s, 30s, 40s and beyond with this catastrophic, terminal disease. Many of us have served on the frontlines, survived combat, only to someday have ALS, a death sentence unlike any other. This is the reality of this service-connected disease.

Too many veterans who have survived combat wounds, amputations, and traumatic brain injuries will not be spared an ALS diagnosis. It is not a matter of if it will happen, but when will it happen. As the neurologist, Stan Appel, MD testified in April 2009 before the Military Construction and Veteran Affairs Appropriations Subcommittee said, "ALS is not an incurable disease. It is an underfunded disease." Ten years later, this disease is still killing veterans. It's devastating for us and our families. It's tragic and it's time for real funding for ALS research.

We respectfully request doubling the funding of the DOD ALS Research Program to \$40 million per year. We, the men and women who wear and wore the uniform, have earned this meaningful investment.

Thank you for joining us in our fight to find cures for ALS.

Respectfully, on behalf of all Veterans and service members with ALS,

Guillermo Garcia, USN Veteran with ALS, TX

Roger Brannon, USMC Veteran with ALS, MD

Lara L. Garey, Elizabeth Dole Fellow and Spouse/Caregiver to a USAF Veteran with ALS, TX

Mandi Bailey, stepdaughter/caregiver to veteran that passed due to ALS, FL

Lura Sawyer, Spouse/Caregiver to USAF Veteran with ALS, PA

Donna McArthur, USAF Veteran & health care provider to Veterans with ALS, AZ

Jeremy Van Tress, MSW, CSWA, PhD Candidate, US Army Veteran with ALS, OR

Mary Ward, MS, MPA, Spouse/Caregiver of a USMC Veteran with ALS, Elizabeth Dole Foundation Fellow, NC

John J. Kenney, US Army Veteran with ALS, MD