## WRITTEN STATEMENT OF JENNIE BELLER, DOLE CAREGIVER FELLOW WITH THE ELIZABETH DOLE FOUNDATION AND VETERAN CAREGIVER, BEFORE THE SENATE VETERANS' AFFAIRS COMMITTEE, UNITED STATES SENATE ON 2018 MISSION ACT, TITLE 1 IMPLEMENTATION

October 21, 2020

Chairman Moran, Ranking Member Tester, and Members of the Committee, thank you for inviting me to share my story as you assess the expansion of VA caregiver benefits under the VA MISSION Act of 2018.

I appear before you today as the caregiver of a veteran. At the same time, I am also a national advocate for military caregivers with the Elizabeth Dole Foundation, and a lawyer who served as a Deputy Attorney General for the State of Indiana.

More than 40 years ago, my husband Chuck was exposed to Agent Orange while deployed during the Vietnam War. The exposure caused diabetes, and the diabetes triggered a stroke.

For the last ten years, Chuck has required 24-hour care. The stroke caused paralysis on the right side of his body, so I assist him with his Activities of Daily Living. Every day begins with me helping him out of bed, moving him into his chair, and assisting him with showering.

Once I get Chuck dressed, I put on his battle gear, which are the braces for his shoulder, hand, and leg. Then, I prepare his breakfast, assist him with eating, and administer his insulin and other medications. At this point, the morning has only just started, but it continues like this for the rest of the day.

Our biggest challenge is Chuck's inability to communicate. His intelligence and memory are unaffected, but he can no longer read or write. He understands about 60 percent of what is said to him. When he attempts to speak, his words come out garbled. As his caregiver, it is my job to help him understand what is going on in any given situation and make him feel that he has been heard, especially during medical appointments.

For my first five years as Chuck's caregiver, I did my best to hold on to my old life. I was entering some of the most professionally fulfilling years of my career, not to mention the highest earning years as a lawyer. I leaned on the Family Medical Leave Act to help me stay employed, but even with that assistance, I barely had time to sleep and fell into destructive self-care habits. Emotionally, I was devastated by the never-ending cycle of caregiving. Considering the sacrifices I was making as a caregiver, I could never understand why VA benefits were denied to me and the millions of other pre-9/11 caregivers, just as I do not understand, now, why we must endure continued delays and drawn-out timelines.

The VA must find ways to streamline the evaluation process. For example, the VA has a decade of medical files demonstrating that my husband needs assistance with every Activity of Daily Living and that I am his primary caregiver. Yet, to apply for benefits, a VA representative was still required to interview me and my husband—who can barely communicate—for two and a half hours. This lengthy process can add stress and anxiety to both the veteran and caregiver. I understand that the VA is trying to gather as much information about the caregiver, veteran, and their home but it is imperative that the interviews accommodate veterans who may not be communicative, like my husband, or who may not be able to sit for the full two and a half hour interview. I am happy to say that our Caregiver Support Coordinator was very accommodating of Chuck and I but can we say the same across the rest of the VA system?

If you multiply the process across the tens of thousands of applications, these efforts could add up to further delays.

The VA should also enforce consistency in the evaluation process. Caregivers sharing their application stories in online communities are revealing significant variances between VA locations, and between the application instructions and how it is put into practice. The most concerning of these inconsistencies is the overreliance on activities of daily living as a measure of required care. Caregivers assisting someone with invisible wounds are struggling to prove the value of their care, and I assure you, their care is saving their veterans' lives.

Resolving these issues is critical because caregivers are counting on these benefits. The VA's financial assistance is not insignificant to caregivers who have to choose between caring for their veteran or paying the bills. I loved my career, but I had to drop out of the workforce. I would have died if I continued working while caregiving, and Chuck would have died shortly after I was gone. However, it's not just about the financial assistance that is invaluable. If allowed into this program, I will have someone who is there to help me in my caregiver journey. These benefits are lifelines to the caregivers and without the love and care from a family member or friend, a veteran may not survive. That is how important caregivers are to their veterans, and that is why allocating these benefits as quickly as possible is so vital.

Despite the challenges I outlined today, I would like to commend both Congress and the U.S. Department of Veterans Affairs for remaining committed to correcting the inequity in VA caregiver benefits. For many years, veteran caregivers have felt voiceless. Today, we finally feel heard.