Statement of Mrs. Julie Guleff
House Veterans Affairs Committee
Subcommittee On Disability and Memorial Affairs
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Chairman Luttrell, Ranking Member McGarvey, Members of the Subcommittee, thank you for the opportunity to testify today.

My name is Julie Guleff, and I am the spouse, former caregiver, and now survivor of 100% service-connected disabled Vietnam Veteran, Stephen Guleff. I come here today to speak in support of H.R. 3833, the *Veterans' Caregivers Appeals Modernization Act of 2025*. This legislation would:

- Allow former veteran caregivers who are now survivors to receive back pay for the care that was provided to the veteran prior to his/her passing if their caregiver application is approved on appeal.
- Require VA to ensure that all documents and medical records related to any application for eligibility in VHA Program of Comprehensive Assistance for Family Caregivers (PCAFC) is uploaded to a single electronic system accessible by all VHA and VA Board of Veterans' Appeals employees who make decisions on such applications.

To understand my strong support for this bill, I need to explain our story. I first met Steve in 2004 after I moved to Florida to care for my mother, following my veteran father's passing. I had been navigating my father's care with the VA healthcare system from a distance since 1999, so when I met Steve, I already had some experience in how it worked. Shortly after we met, I learned he was a struggling Vietnam veteran. We quickly became friends, and I offered my assistance in navigating the VA, as he was largely unfamiliar and very cautious about trusting the system.

It wasn't too long before Steve was getting the help he needed and beginning to allow and embrace those practitioners he was fortunate to encounter. As I helped him learn to trust, find his way around, find "guys like him," and take advantage of all the services available, he began showing progress in all areas of his life. It was then that things took a turn. Between the PTSD diagnosis and treatment, additional physical and mental health issues uncovered, and the growing impact of Agent Orange exposure, he started to crumble before my eyes. I steadfastly stood with him and helped him face all of those challenges while reminding him he was not alone in this struggle. I would not give up when things got difficult.

Fast forward 5 YEARS. Steve was finally sticking with his services and programs at the West Palm Beach VA Medical Center. I was still working 3 jobs to provide for my children and mother but was ready to reactivate my nursing license to continue my career I had planned for most of my life. However, as our relationship had transformed from best friends to something more and recognizing his growing needs, I put my life on hold for a greater purpose as "caregiver" to Steve.

As time progressed, so did Steve's challenges. He remained active in his treatments at the VA, worked tirelessly with his doctors, but his health progressively got worse. The medication list was now pages long, and I carried these pages with me everywhere to present to each provider.

We had only been married a year, but now my role changed again. I was full time caregiver, nurse, and wife. With those titles my personal goals and career vanished. I had 3 jobs, but none of them came with a salary. Because I couldn’t work due to my caregiving responsibilities, we were 100% dependent on Steve's disability payments. With the increasing out-of-pocket medical expenses, such as non-formulary prescriptions, durable medical equipment that was too difficult to get through the VA process, and needed safety modifications to our home, our debt grew daily.

Steve's health needs were clear and documented. He couldn’t drive, go anywhere by himself, eat, self-sustain, or manage his own affairs to any degree. The PTSD was unmanageable and often frightening. The outbursts (often brought on by his failing health that angered him), nightmares, and "night patrols" on high alert, which meant barricading doors and windows to keep him in and "others" out, required 24 hour a day vigilance. It was overwhelming to say the least and beyond exhausting.

In 2017, Steve's issues compounded once again. His health was becoming increasingly unstable and difficult. As a nurse, I read EVERY report, note, and bloodwork result, and diligently researched EVERYTHING looking for answers or possible treatments. It was then that I saw his PSA bloodwork and noted a big change. On top of everything else, we were now fighting prostate cancer.

In 2018, we moved to Daytona Beach and were very fortunate for Steve to be able to get a VA-backed mortgage to buy a house. The downside was that, by this time, I did not have the credit to be added to the mortgage. Due to my caregiving responsibilities, I hadn’t worked since 2010, had significant debt, and definitely could not leave Steve to go to work.

It was in late 2019, after the VA’s approach of “watch and wait,” that we learned the prostate cancer had progressed to STAGE 4 PLUS. Steve completed 55 consecutive days of radiation, which caused severe side effects. The radiation left Steve with even more challenging healthcare needs. He was now bedridden, completely incontinent, and unable to stand, walk, or attend to personal hygiene needs. Moreover, the radiation furthered his dementia, requiring more oversight. And then the COVID-19 pandemic hit, and the isolation of COVID lockdown made it all even more overwhelming for both of us.

On October 1, 2020, we were excited to learn that the PCAFC program opened to Vietnam Era Veterans. I immediately applied to get some financial relief as, according to the regulations, I thought my husband was more than qualified. His records reflected and documented him as housebound, bedridden, unable to complete any activities of daily living other than barely holding his own fork. I wheeled him to the bathroom and physically held him while he attended to that; had to enter the shower with him and wash him on a chair as he could not do that unaided; brushed his teeth; and managed all medications. He was unsafe if left alone for even a moment. If unwatched, he would find and take medication, try to get outside and wander off, and, if he found the car keys, he would attempt to get to the car and drive. He had significant dementia and often was unable to think or act coherently. He was a danger to himself and others and required constant monitoring. I had to hire someone to stay with him if I had to leave the house for any reason, such as grocery shopping. Our first PCAFC application was submitted by November 2020. Months passed, and we completed all necessary paperwork and documentation.

Due to the pandemic, our home visit and interview were done virtually. It must be noted that these virtual evaluations were not necessarily an accurate representation of our reality, as it's hard to see through a phone camera all of the medical equipment and the piles of pill bottles I had to hide from my husband. It really would have been more accurate if an actual person had been there. My husband lived with fear, shame, and guilt of his situation and went to great lengths to not let people see him in his debilitated state. He always wanted to make people like him and always put his best face forward for the brief time they spoke to him. He could be quite convincing and charming, but his medical and mental health records told a different story. Those records show a broken and terminally ill man living in fear, shame guilt, and suffering. The suicidal ideations were frequent and long lasting. Keeping him safe was my top priority and all-consuming.

I received the notes and records from the virtual evaluations while we waited for a decision. There were glaring differences noted as to what was actually happening. The PCAFC coordinators seemed to change weekly, making continuity of care and sharing of information difficult. We were handed off to patient advocates and social workers, and each contact was a different person.

I spent endless hours on the phone, writing letters, emailing, faxing, hand delivering documents, and correcting errors with PCAFC documentation for what appeared to be a clear case for approval. The first denial came in early 2021, with the reason given that the "Veteran does not need six months of continuous care," a requirement under PCAFC. That was inconceivable to both my husband and me. We had already been through YEARS of continuous care—home health, physical and occupational therapy, retrofitting of portions of our house to accommodate his disabilities, and countless pieces of medical equipment all over the house. The more time that passed, his needs grew. We were heartened in March of 2022 when, recognizing flaws in the system, the VA announced that it was pausing dismissals from the program while the agency reviewed the eligibility criteria. Today, over 3 years later, caregivers are still waiting for the new regulations to address the problems.

By the end of 2021, Steve's diagnosis was terminal. The cancer had metastasized. He was in pain and always searching for relief. Life was getting impossible. He would remain in bed for days at a time. He was so angry and frustrated, and he was having tremendous trouble thinking, communicating, and understanding what was happening to him. He often refused to eat and was getting weaker by the day. Keeping him safe, clean, and fed was becoming more and more difficult. Yet I persevered. I could see where this was going and was working in the background to prepare for the end.

In August 2022, we went bankrupt. Our finances had all been spent, and we were buried in medical debt. We appealed the PCAFC decision multiple times. To be clear, if it had been approved, it wouldn’t have solved all our problems, but it absolutely would have helped.

Steve passed away on October 6, 2022. Days after his death, I received a call from our mortgage holder asking me when I would be vacating our home. The company made it clear that it could not hold a mortgage for a deceased veteran. As I was not credit qualified and had no income, no employment, and 12 years of history with no "job," there was no possible way to keep my home. I had no choice but to sell it quickly and take what I could get before they took it. In a matter of moments, it was clear I would become homeless. After years of sacrifice of career, credit, savings, and personal health, I was now widowed, alone, destitute, and heartbroken. Sadly, I am not alone; my situation is only one of many.

Our PCAFC case was still open at the time of my husband’s death, even after 2 years of fighting for a favorable decision. The overwhelming challenge of gathering and adding documents to the veteran’s medical record for both the Veterans Health Administration and for review of the Board of Veterans Appeals is impossible in its antiquated current form. I struggled for years to connect the dots between providers both in the VA and outside to make sure records were up to date, inclusive, and complete. I often went from provider to provider, office to office, doctor to doctor to demand printed and digitalized copies of each and every note, treatment, and diagnosis. I would then hand carry them into the VA to be added to Steve’s records, only to be told, “These must all be scanned by a live person into the record. We don’t have the manpower—just hold on to it until we ask for it.” I physically carried copies of everything with me to every appointment to beg for someone to add pertinent information to Steve's records. Community care was even more of a challenge; outside records sometimes never made it into Steve’s file for use in treatment plans and certainly not for PCAFC eligibility.

Despite my best effort of hand carrying records and calling, writing, and emailing requests to update records, it RARELY, if ever, happened. This failure of an antiquated record-keeping system left huge gaps in care and treatment.

In a time where it is easy to instantly transmit documents digitally, it is hard to believe that the VA is as far behind as it is. I acknowledge changing an entire system to update technology is a huge challenge, but I also believe it is long overdue. Had this option been available, I may have stood a chance at PCAFC approval before my husband died.

In the wake of losing Steve, I was so frustrated with the denials for PCAFC that I made it my mission to follow through with our quest. In 2023, I filed our case before the Board of Veterans Appeals, and, while I knew it was a long shot, I was determined to stand strong. I built my case with the mountains of evidence and records I had from my husband's decades with VA direct and community care and, ultimately, I went before a judge to plead our case in December 2024. I spoke to him for over an hour. He asked numerous questions and, by the time I was done, he was in tears at all of the pain and anguish we had been through .

Unfortunately, in March of 2025, almost 5 full years after we first applied, we were denied again, with the following Conclusion of Law:

> "Due to the death of the veteran, the appeal for eligibility of PCAFC benefits must be denied as a matter of law."

The Board also noted that it was only able to consider "evidence of record at the time of the agency of original jurisdiction (AOJ) decision…". After all our challenges—COVID interfering with appropriate care and evaluations, flawed regulations, changing staff, and the lack of appropriate records sharing, we were ultimately denied because the VA simply outlasted my husband.

The caregiver experience is a challenging and difficult one, and it is impossible to explain unless you have lived it. It is a job that no one chooses to have but is often necessary to ensure the best possible outcome for the veteran.

Caregivers take on this challenge out of love for the person who has served and suffered. It is not a singular act. It requires that one give of themselves endlessly, most often at great sacrifice to self. A fellow caregiver once told me one of the most poignant things I have ever heard. "A Veteran does not heal in a vacuum." A truer statement has never been spoken. It takes all of us—doctors, nurses, and caregivers—to be a part of the healing process. How can we do less than care for them?

Taking care of these veterans and helping them achieve the best quality of life they can have, however, also requires supporting those caring for them—, whether they be doctors, nurses, or family members

I THANK YOU ALL for inviting me here today to listen to my story. I tell it not for personal gain, as it is likely too late for me, but for those who are still caregivers and those yet to be. While PCAFC would not have solved my issues or changed the outcome, it most certainly would have helped and made it more tolerable.

Thank you for your time today, and I look forward to your questions.