

Testimony of Shelly Hoover, EdD  
Before the Senate Committee on Veterans' Affairs  
Oversight Hearing: Strengthening Services for Veterans with Spinal Cord Injury and Disorder

Chairman Moran, Ranking Member Blumenthal, and Distinguished Members of the Senate Committee:

Thank you for the opportunity to appear before you today. My name is Dr. Shelly Hoover, and I am a veteran of the United States Navy. For 12 years, I have been part of the Spinal Cord Injury and Disorder System of Care, and I stand here today as a testament to the life-saving care provided by the Veterans Health Administration. This testimony is the culmination of a decade spent advocating for the more than 4,000 veterans currently living with ALS.

My journey with ALS began in 2013. Initially, the VA's support felt focused on end-of-life care, a system designed to manage my death rather than empower my life. But I had a different plan. I proactively sought out an ALS multidisciplinary clinic and worked to redefine my path. That experience drove me to seek a seat at the table with the **VA ALS Executive Committee (ALSEC)**.

Working alongside a team of fellow advocates, we built a relationship of trust with the ALSEC. We urged them to make the ALS System of Care more user-friendly for veterans and their caregivers, and they listened. Under the visionary leadership of Drs. Illeana Howard and Sharyl Martini, the committee achieved significant improvements without any additional compensation for their work. Their dedication led to the creation of:

- A network of **ALS Coordinators**, including nearly all of the 170 VA medical centers.
- A comprehensive **website** to help veterans and caregivers navigate their care.
- An internal **training program** for new coordinators and other departments.

This model, which integrates feedback from those with "boots on the ground" experience, demonstrates the power of collaboration and mutual trust. It is a gold standard for enhancing the veteran experience and improving morale for VA employees who care so deeply for those they serve.

Based on my lived experience, I offer two recommendations for continued improvement and future success:

### **Recommendation 1: Empower Stakeholders**

All departments and workgroups within the Spinal Cord Injury and Disorder system must develop trusting relationships with both internal and external stakeholders. As the ALSEC has demonstrated, this approach enhances employee morale, empowers stakeholders, and, most importantly, improves the quality of care and the overall experience for veterans.

### **Recommendation 2: Ensure Full Funding**

Congress must ensure the Veterans Health Administration is **fully funded**. In addition to budget cuts, Congressionally allocated funds for special diagnoses, like ALS, cannot be spent due to VA-imposed hiring freezes and caps. Can that be corrected? These funding shortfalls have had a direct and devastating impact on my health and safety.

I recently experienced severe complications after a VA pharmacy, due to budget cuts, was unable to provide the liquid form of a prescribed chemotherapy drug. I suffered severe burns across my chest and pelvic region, an extreme and avoidable outcome. Delays are now a constant risk. For example, my replacement mic-key button, used for feeding and medications, is over a month late. How long before my current one breaks down and my stoma becomes infected? Life-sustaining breathing and nutrition supplies that were once readily available now face delays of weeks or even months. For a person with my condition, this is not just an inconvenience—it's a grave threat. I will not die from ALS; I will likely die from infection, a risk dramatically increased by these supply delays.

Some may suggest that private **Community Care** is the solution, noting its budget was recently doubled. However, with one exception, my personal experience has been a disaster. I've endured six-month delays and lost referrals, forcing my husband to spend countless hours on the phone. In one instance, a private medical office initially refused to treat me due to my tracheostomy, a clear violation of my rights.

By contrast, I have never experienced a delay or faced discrimination from the Durham VA Medical Center. It is clear to me that the VA is the best choice for Veterans.

My family's legacy is deeply tied to military service, with eight of my immediate family members having served in the Army, Navy, and Marines. I am profoundly grateful for the exceptional care the VA provides, and my grandchildren are thankful that I am still here because of it.

To continue this gold standard of care, the Spinal Cord Injury and Disorder system must actively seek input from external stakeholders. And, above all, Congress must fully fund the VA to protect the health and lives of current and future Veterans.

Thank you.