

STATEMENT OF SONYA SOTAK
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BEFORE THE
HOUSE COMMITTEE ON VETERANS' AFFAIRS
ON
"A CALL TO ACTION: MEETING THE NEEDS OF THE SPINAL CORD INJURY AND
DISORDERS (SCI/D) VETERAN COMMUNITY"

JUNE 13, 2024

Chairman Bost, Ranking member Takano and members of the committee, it is my honor to be invited to testify today on behalf of I AM ALS and representing approximately 6,000 veterans living with ALS in the United States. My name is Sonya Sotak and I am the Chief Government Affairs Officer for I AM ALS. I AM ALS is a small but mighty non-profit organization for people living with ALS. Our organization is a patient-centric driven organization, and many of our activities and policy efforts are driven by and collaborated with the actual community. We were established in 2017 by Brian Wallach and his wife, Sandra, after Brian was diagnosed with ALS at the age of 37 on the same day they brought their second daughter home from the hospital. Since then, I AM ALS has been privileged to partner with many of you here today to help move significant pieces of legislation through Congress to support people with ALS. First, the ALS Disability Insurance Access Act, which passed with unanimous support in the House of Representatives in 2020; next, we worked with many of you to get the ACT for ALS passed in 2021, again, with overwhelming bipartisan support. Also, many of you on both sides of the aisle have helped the community increase funding for the ALS research program at the Department of Defense. For the last two years, I AM ALS and the entire community of ALS organizations have urged Congress to double this funding since the incidence of ALS among veterans is at least two times that of the general population.

We also know that the Department of Defense ALS research program is receiving more than double the amount of quality research proposals that need grant support - proposals that they cannot approve at the current funding amount - and represent strong science that otherwise might be able to address the needs of veterans with ALS. We know that the proposed FY25 funding measure remains at \$40 million but we continue to urge Congress to find a way to increase resources for this program for FY25 and invest in research that can address this horrible disease and help the 1 in 6 people with ALS who are veterans.

We thank each of you and all of Congress for these important accomplishments and truly appreciate the bipartisanship effort that it took to achieve each of these advancements and the willingness for everyone to work together to pass legislation improving the lives of people, including thousands of veterans living with ALS.

As I mentioned, our organization is driven by community members affected by ALS themselves, thousands of volunteers taking action. Our veterans team created by incredible veterans and caregivers for veterans living with ALS is one of our most powerful and impactful committees. These veterans with ALS and their loved ones identify barriers, create tools and toolkits, and advocate to ensure that the VA benefit and health care system is easier to navigate and provides better and more accessible services. Sadly, we know all too well that this advocacy is needed to ensure basic, supportive care for veterans with ALS. As an example, our toolkit helps veterans identify and receive existing veteran benefits once they are diagnosed with ALS. This basic guide is over 45 pages long - that is how complex the system is for our veterans at a time when they are already overwhelmed and should be focusing on maximizing life with family rather than navigating a complex, bureaucratic healthcare system. Lack of knowledge of the VA system can result in frustration and delays in service. Because ALS can progress rapidly, delays need to be avoided at all costs. Congress recognized this when you passed the ALS waiver eliminating the SSDI waiting period. Our veterans with ALS and their families deserve the same recognition when accessing benefits. We urge you to work to ensure that all the veterans not yet diagnosed will be taken care of and hopefully enter a VA system that provides stronger and better access to health care and support services than they have had while enduring ALS.

As the Chairman and committee members know, ALS is recognized as a one hundred percent service related disease. Statistics vary but we know at a minimum members of our military are two times more likely than civilians to develop ALS. This stat skyrockets to ten-times when examining post-9/11 Airforce veterans. We also have seen data that estimates approximately 5000-6000 of the 30,000 people with ALS in the United States are veterans or again, about sixteen percent. I say approximately because the world of ALS lacks solid data for many reasons but one key reason is the significant delay and complexity in diagnosing ALS. The prevalence of misdiagnosis is incredibly high and many people may never receive the right diagnosis or receive their diagnosis too late for being factored into national data. We also have a national system that does not compel data collection and is based on self reporting. This is such a complex topic it's worthy of its own hearing another day up here.

Before I dive into access to home health care that is critical for our veterans with ALS I want to set the table with some critical facts.

First, I want to be sure that the committee and everyone here today knows that ALS, or Lou Gehrig's disease as it is often known, is 100 percent fatal.

Nobody survives ALS and most die within 2- 5 years after being diagnosed. When people finally receive a diagnosis they are told to go home - get their affairs in order and prepare to die. So every one of our veterans that develop ALS will die from it no matter how hard they fight or how strong their valor. Every single veteran will lose their battle with ALS.

ALS is a neurodegenerative disease that affects nerve cells in the brain and spinal cord. ALS is a wicked, cruel disease that slowly paralyzes a person, taking away their capacity to be self sufficient and eventually losing their ability to breath.

ALS was determined to be a one hundred percent service connected disease by the Department of Veteran Affairs on September 23, 2008. Following that decision it has been a tough and multifaceted journey for a multitude of reasons within the VA to provide the necessary, appropriate and equitable support for Veterans with ALS. The VA issued the VHA directive 1101.07 the ALS system of care in August of 2021. The

intent of this directive is to ensure that all care, services and access to equipment is known to veterans and their families including the responsible parties for ensuring access. Too often while managing ALS, many of our veterans and their families have to take significant time to advocate for themselves and often it is to explain to the VA what their VA benefits actually are as a veteran with ALS.

The VA's Spinal cord injuries and disorders (SCI/D) centers are designed to provide comprehensive care for veterans with spinal cord injuries and related injuries. However, these centers often face challenges fully meeting the needs of veterans with ALS due to the multifaceted nature of ALS. Part of the challenge is the SCI/D's are set up for your typical spinal cord injury which are often a static disease while ALS is a progressive & increasingly complicated debilitating disease.

Specialized care: ALS requires specialized neurological and respiratory care that is often not fully available at SCI/D centers. For instance, expertise in managing progressive muscle weakness and continued respiratory failure is something lacking at these centers. ALS requires multidisciplinary care with a coordinated approach by a team of health care professionals from a variety of disciplines to manage the complex needs of a Veteran with ALS. The goals are to improve the quality of life, slow the disease progression and provide much needed psychological and social support. This is too often not possible and simply not how the SCI/d's are set up and they often lack the staffing capacity and training for meeting the needs of our veterans with ALS. Expertise is often lacking for managing progressive muscle weakness and repository failure at the centers.

Advanced respiratory Support : Veterans with ALS often need advanced respiratory support, including non-invasive ventilation or mechanical ventilation which is often not the focus of SCI/D centers.

Comprehensive team : As I outlined earlier, the SCI/D centers do not have all the specialists available for ALS veterans or do not have the same level of coordination and collaboration as some ALS clinics or even what is available through accessing care in a veterans home setting.

SCI/Ds often have Insufficient focus on ALS specific interventions including:

Assistive technology:

Veterans with ALS often need specific assistive technologies such as augmentative and alternative communication devices which may not be readily available or supported in the centers.

Adaptive equipment

Too often the centers focus on spinal cord injury specific equipment and not the evolving and very demanding and intricate needs of ALS veterans.

Psychological and social support gaps

The specialties counseling and training needs for managing the extensive emotional and psychological support needed by ALS veterans and their families as a result of the rapid progression and terminal nature of the disease is often found to be lacking at the centers.

Palliative and end of life care

Many of the SCI centers do not have integrated palliative care services tailored to the specific needs of ALS veterans. ALS support requires significant palliative care and end of life planning which has a unique perspective and approach for managing ALS symptoms and quality of life,

Another key challenge is the location of the 25 centers. Many of them are simply not near many of our veterans living with ALS and not easily accessible for the veterans scattered around the country managing the very debilitating disease of ALS.

I AM ALS and our veterans community believe an important component of their ALS care is being able to remain in their home. For this reason, I AM ALS fully supports the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act. While this comprehensive bill contains many important measures, I would like to focus on the pieces that are most important for veterans with ALS - The Elizabeth Dole Home Care Act contained in this comprehensive package is significant for veterans with ALS for several reasons:

Most significant for our community of veterans with ALS is that the legislation increases the expenditure cap for non-institutional care from 65% to 100% of the cost of the closest VA Community Living Center (CLC). This would allow the most vulnerable veterans and caregivers the support they need to stay in their homes, often leading to better outcomes for veteran families, especially veteran families grappling with ALS.

The removal of the cap would help families care for their 100% service-disabled veterans with ALS. Because of the mandated cap, families constantly have to fight with the VA to get the appropriate support in their home so their veteran can continue to enjoy being near family rather than being sent away to a facility which is often hours away from the much needed support system of family and friends. For many veterans remaining in their home with friends and family during their hardest battle managing ALS is paramount. Staying in their home with loved ones improves their quality of life but it can also help reduce medical complications.

Let me share the story of Navy veteran Garrett who served as part of the Seabees, a construction battalion with tours in Iraq and Afghanistan. Garrett's journey with ALS was challenging and started with him being forced to make the longer journey to Milwaukee because they had the VA ALS clinic even though the Iron Mountain VA was much closer to his home. As the disease progressed, and these road trips were no longer feasible Garrett had to start a Go Fund Me campaign to try and offset the additional home health care he needed that wasn't provided by the VA. Eventually, he did hit the cap. It was far more complicated - his wife was overwhelmed with managing his care alone for so many hours to prevent hitting the 65% cap, while also being a single parent for their three young children. Then, Garrett had to get a trach. After all this chaos, Garrett hit the cap and had to go to an institution. Garrett tried his best to maneuver the system so he could get back home with medical support from home care. Unfortunately, the current structure would not afford him that final return home and Garrett made the decision to remove his trachea and end his own life rather than spend his days alone in the center far from his family and without the daily support from friends, family and his kids. Garrett is not the only veteran that we know that chose to end their life early rather than endure being in a VA institution that failed to meet their medical needs and lacked an appreciation for the care they needed as a veteran with ALS. Even one veteran is one veteran too many to be isolated from friends and family because of the distance from

their communities and family when forced to leave their homes for care because of a cap limiting their access to support in their home .

Comprehensive care for veterans with ALS. As I shared earlier - ALS is a neurodegenerative condition and as the disease progresses, veterans with ALS require extensive and specialized care. The Elizabeth Dole Home Care Act ensures that our nation's veterans receive comprehensive home-based care tailored to their complex needs, improves their quality of life and allows them to remain in a familiar and comfortable environment with their families, friends or loved ones.

Also included in the Elizabeth Dole Home Care Act is the Veteran Directed, Home-Based Primary Care and the Homemaker Home Health Aide programs that support the care and quality of life of veterans and caregivers, especially at home and can serve as a lifeline for veterans and caregivers in need. This program, a joint offering from the VA and U.S. Department of Health and Human Services (HHS), offers veterans and caregivers greater choice and control over their care and services by allowing participants to utilize friends and family members to provide unskilled care including transportation support and other services to support the veteran in their home. Veterans and caregivers can supervise their own employees and hire additional support during the hours that are needed rather than being subject to agency hours and restrictions. In addition, this program has been especially helpful to those who struggle to find appropriate care in their homes either due to contracted agency employee absences or the general dearth of HHA providers around the country.

Support for Caregivers.

The Elizabeth Dole Act recognizes the important role of caregivers, often family members, in managing the daily needs of veterans with ALS. By providing resources, training and financial support to caregivers, the Act helps reduce the emotional and financial burdens and allows them to provide better care and support for our veterans. Being a caregiver is hard work; being a caregiver for a person with ALS is beyond daunting and incredibly exhausting.

Access to Medical Services.

The medical needs for veterans with ALS are complex and frequent including physical therapy, respiratory care and many other specialized treatments. The Elizabeth Dole Act facilitates access to these necessary treatments at home, reducing the need for hospital visits or visits to SCI'D centers that often lack the personnel and speciality training needed for minimizing the risks for people with ALS, including infections, complications and sadly, but very frequently medical professionals who simply are not familiar with ALS and unintentionally create more complications when they treat our veterans with ALS.

Quality of Life

Helps maintain a sense of independence and dignity for veterans while ensuring they receive the medical attention and daily assistance they need while remaining in a safe and comfortable home environment with advocates around them to ensure their needs are being met.

Economic benefits

Home based care is more cost effective than institutional care. By raising the cap to 100% and supporting veterans with ALS receiving home care the EDHCA helps manage health care costs more efficiently while allowing veterans to receive high quality personalized care.

I AM ALS is so pleased that the Elizabeth Dole Home care Act is bringing greater awareness of the challenges and needs of veterans living with ALS especially those that need more support than the current SCI centers can provide. This bipartisan legislation advocates for and demands higher quality care including respect and dignity of care in their homes with loving friends and family. This legislation will ensure that our nation's veterans with ALS receive the respect and care they certainly deserve after their service to our country.

I would be remiss if I didn't take the honor and privilege of engaging with Chairman Bost, Ranking Member Takano and the entire committee without mentioning other key priorities for veterans with ALS that we hope you will support and guide through Congress quickly for our veterans with ALS

As I mentioned earlier, I AM ALS supports doubling the funding for CDMRP ALS Research at the Department of Defense. Multiple studies have reported that Veterans are significantly more likely to be diagnosed with ALS than those who did not serve in the U.S. military. While the specific cause of this increased risk is unknown, the correlation between military service and ALS is well-established so we encourage a significant investment in researching this disease and finding a way to treat ALS for the thousands of veterans that will develop this horrific disease. We know that the additional research projects exist and are simply not being funded because of the lack of resources being allocated. We urge you to increase the funding to \$80 million for FY25.

I AM ALS also urges Congress to pass the Justice for ALS Veterans. This bipartisan legislation would fix the unfair policy that denies benefits to the surviving spouses of veterans who died from ALS by providing the surviving spouse with the DIC kicker without meeting the eight years of disability requirement. Unfortunately, because most people with ALS, a recognized service-connected disease, live fewer than eight years from diagnosis, the surviving spouses of veterans with ALS have been unfairly denied this benefit. The same spouses who may have quit their jobs to take care of their loved ones who progressively lost muscle control, became paralyzed and relied heavily on their caregiver to stay alive.

Closing

I AM ALS is incredibly appreciative for all that Congress has done for the ALS community in a bipartisan, collegial manner, but the ALS community needs Congress to do even more for this 100 percent fatal disease with no real treatment options. And we need you to do more with a specific focus on our veterans with ALS. We should not allow a system of care to continue that sees more veterans like Garrett decide that ending their lives is preferred to enduring a VA institution that fails them that doesn't provide the support and medical care they need, and certainly doesn't have the staff available or trained to meet their complex medical needs despite their sacrifices and commitment to our nation through their military service. I AM ALS encourages the Committee and Congress to continue working together without politics and to help move important measures forward including the Elizabeth Dole Home Care Act as part of the Elizabeth Dole 21st Century Veterans healthcare and Benefits Improvement Act. Our veterans with ALS who have sacrificed for our country and selflessly served our nation deserve to have access to home based care. They need all of you to keep working

together to support them and support their families as they are in their final battle against a wicked, cruel disease.

Thank you for your time and know that the ALS community appreciates your efforts and continued work together in Congress for people with ALS, especially our veterans. For this reason we urge you to work together to get the Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act passed this year on suspension so critical services are made available for veterans with ALS.

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